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LIVING WITH THALASSEMIA: UNDERSTANDING THE DUAL FACETS OF THALASSEMIA INCLUDING PUBLIC AWARENESS AND PATIENT COMPLICATIONS

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Abstract:

Thalassemia, a genetic blood disorder, remains a significant public health concern, warranting widespread awareness and effective management strategies. This study aimed to evaluate awareness levels and complications associated with thalassemia among a diverse cohort. Data were collected from two groups: 306 respondents for awareness assessment and 100 thalassemia patients for complications analysis.

Awareness of Thalassemia: Among 306 respondents, the majority (75.8%) demonstrated awareness of thalassemia, yet only 21.9% had undergone thalassemia screening. Encouragingly, 73.9% expressed willingness to undertake the test, with 73.2% agreeing on pre-marital screening. While 56.9% recognized thalassemia as a genetic disorder, 86.9% advocated for education about the condition in academic institutions. However, 53.3% were unaware of its complications, underscoring the need for enhanced public health education through seminars and symposia in schools, colleges, and universities.

Complications of Thalassemia: A cohort of 100 thalassemia patients, comprising 44 males and 56 females with an average age under 20, was assessed. Notably, 78% reported low energy levels, and 62% experienced fatigue despite adequate sleep. Additional complications included low hemoglobin levels (68%), anemia (60%), weight loss (28%), and menstrual irregularities among 25% of female patients. Gastrointestinal (29%), respiratory (29%), and sleep disturbances (58%) were prevalent, alongside a history of exposure to toxic chemicals (33%). Iron overload, a common complication due to frequent blood transfusions, necessitated iron chelation therapy to prevent organ damage. Chronic illnesses were relatively rare, with only 8% reporting kidney disease or autoimmune disorders, and 2% had undergone radiation or chemotherapy.

Conclusion: While a significant proportion of respondents are aware of thalassemia, actionable knowledge remains inadequate, as evidenced by low testing rates. Comprehensive educational initiatives are critical for increasing awareness and encouraging proactive measures, including pre-marital screening. On the clinical front, thalassemia patients endure a spectrum of complications, emphasizing the need for integrated care strategies encompassing routine monitoring, blood transfusions, iron chelation, and psychological support. Strengthening healthcare delivery and fostering trust in medical services can significantly improve the quality of life for thalassemia patients.

Future Implications: This research offers valuable insights for healthcare professionals, policymakers, and advocacy groups. It highlights the importance of targeted educational campaigns and resource allocation to mitigate thalassemia's burden. Additionally, the findings can inform policy development and drive advancements in clinical care, ultimately benefiting patients, families, and healthcare systems at large. Further studies are encouraged to explore innovative interventions to improve patient outcomes and raise community awareness.

1. Thalassemia:

Thalassemia can be defined as hereditary red blood cell disorder that causes anemia due to defective genes that in turn code for the synthesis of globin proteins in the body.[1] Thalassemia is the foremost common shape of acquired anemia around the world which is characterized by the diminished or annulled generation of either the alpha-like (alpha thalassemia) or the beta-like (beta-thalassemia) globin chains that are produced to form hemoglobin tetramers

(alpha2gamma2, HbF; alpha2beta2, HbA;alpha2delta2, HbA2) during the fetal and postnatal life.[2]

There are two main types of thalassemia like α-thalassemia and β-thalassemia. Thalassemia is an acquired disease, meaning that at least one of the guardians must be a carrier for the disease. It is caused by either a hereditary transformation or erasure of certain key quality parts. If a person receives a beta thalassemia trait from their father and another from their mother, they will have beta thalassemia major. If a person receives an alpha thalassemia trait from their mother and the normal alpha parts from their father, they would have alpha thalassemia trait (also called alpha thalassemia minor).[3] Both α- and β-thalassemia include the following forms:

1.1 Thalassemia major

with the imperfect genes from both parents, Severe anemia, Enlargement of the spleen and body deformities due to bone marrow expansion are clinical characteristics of thalassemia major.[4]

1.2 Thalassemia minor

with the defective gene from only one parent), Mild or no anemia, normal life expectancy and occasionally, slight enlargement of the spleen may occur in thalassemia minor.[5] Clinical signs typically appear a few months after birth. Commonly associated with infections. Stunted growth usually becomes evident around the age of four. Physical features may include a protruding upper jaw, prominent cheekbones, and easily fractured bones due to marrow expansion.[6]

2. Anemia:

Concurring to WHO criteria, the anemia is characterized as having a blood hemoglobin (Hb) concentration less than <13 g/dL in a male patient and <12 g/dL in a female patient.[7] Anemia is a widespread medical condition characterized by a deficiency in the number of red blood cells (RBCs) or the amount of hemoglobin in the blood, leading to reduced oxygen-carrying capacity.[8] The reduction in oxygen available to organs and tissues when hemoglobin levels are low is responsible for many of the symptoms experienced by anemic people. The consequences of anemia include general body weakness, frequent tiredness, and lowered resistance to

disease.[9] Anemia can be a particularly serious problem for pregnant women, leading to premature delivery and low birth weight. It is of concern in children since anemia is associated with impaired mental and physical development.[10] Anemia may be caused by several factors like Nutrient deficiencies through inadequate diets or inadequate absorption of nutrients, Infections (e.g. malaria, parasitic infections, tuberculosis, HIV), inflammation, chronic diseases, gynecological and obstetric conditions, Inherited red blood cell disorders. The most common nutritional cause of anemia is: Iron deficiency, although deficiencies in folate, vitamins B12 and A are also important causes.[11] Hemoglobin (Hb) is a tetramer composed of two α-globin and two β-globin chains, each containing a heme molecule. Deficiencies in these structural components can lead to Hb deficiency or anemia.[12]

2.1 Thalassemia induced anemia:

In people with β-thalassemia, the lopsidedness between α and β globin chains comes about within the aggregation of overabundance α-globin chains, which frame insoluble totals in erythroid precursors, causing cell harm and death.[5] This process leads to ineffective erythropoiesis and contributes to chronic anemia.[13] The patients with thalassemia major may be fatal or often develop severe anemia in the early childhood. The patients with the minor form of α- or β-thalassemia may have no clear iron deficiency within the young-age stage, but they may create gentle or direct hypochromic and microcytic anemia in the middle-age or old-age stage depending on the degree of α-globin or β-globin chain deficiency.[7] The patients with a typical thalassemia trait-induced anemia (TTIA) usually have a higher RBC number (>5 M/Ml usually), a lower MCV (<74 Fl), a lower Mentzer index (<13), a normal serum iron level, and a higher RDW-CV (>15%) .[14]

Differential diagnosis between iron deficiency anemia (IDA) and thalassemia trait-induced anemia (TTIA).

Microcytic anemia	IDA	TTIA
Hemoglobin concentration	Men <13 g/dL Women <12 g/dL	Men <13 g/dL Women <12 g/dL
Red blood cell (RBC) number	<4 M/μL	>5 M/μL usually
Mean corpuscular volume (MCV)	<80 fL	<74 fL
Mentzer index (MCV/RBC)	>16	<13

Figure 1[7] Differential diagnosis between IDA and TTIA

The IDA patients often have a reduced RBC number (<4 M/μL), but the TTIA patients usually have a higher RBC number (>5 M/μL usually), probably due to bone marrow compensation to make a great number of microcytic RBCs. The Mentzer index is a good biomarker for clinical diagnosis of a typical IDA (the Mentzer index >16) and for clinical diagnosis of a typical TTIA (the Mentzer index <13). For a basic differential conclusion between IDA and TTIA, a total blood count (CBC) and serum iron and ferritin (an iron capacity protein) level examinations are ordinarily sufficient for giving the blood information for the clinical conclusion.

2.2 Symptoms:

There are several types of thalassemia. The signs and indications you've got depend on the sort and seriousness of your condition. Thalassemia signs and side effects can incorporate fatigue, weakness, pale or yellowish skin, facial bone distortions, moderate development, stomach swelling, dim urine. A few babies appear signs and indications of thalassemia at birth; others create them amid the primary two a long time of life. A few individuals who have as it were one influenced hemoglobin quality do not have thalassemia indications.[15]

3. Pathology:

3.1 Genetic basis:

Thalassemia emerges from hereditarily decided variations from the norm within the amalgamation of one or more of the polypeptide chains of globin. Different forms of thalassemia are distinguished by: Which polypeptide chain(s) are affected, Whether the affected chains are synthesized in reduced quantities or not synthesized at all, Whether the disorder is inherited from one or both parents.[16]

3.2 Polypeptide chains:

Hemoglobin consists of various polypeptide chains including alpha (α), beta (β), gamma (γ), delta (δ), and epsilon (ε). Involvement of the α and β chains is most common, while involvement of γ or δ chains is rare. No thalassemic clutter is known to include the ε-chain.[17]

3.3 Treatment strategies:

Fitting objectives of transfusion treatment and ideal security of transfused blood are the key concepts within the convention for schedule organization of ruddy blood cells to patients with thalassemia. The major goals are, Use of donor erythrocytes with an optimal recovery and half-life in the recipient, achievement of appropriate hemoglobin level, avoidance of adverse reactions, including transmission of infectious agents.[18] Splenectomy is the prescribed intercession to decrease over the top blood utilization and ensuing extreme iron over-burden. In any case, doctors ought to keep a protected approach towards splenectomy since of the high malady burden related with splenectomy.[19] Current strict transfusion regimen and chelation has considerably reduced the incidence of splenomegaly and iron overload in transfusion-dependent thalassemia patients. In the last few years, a new gene editing technology called CRISPR/Cas9 has helped doctors make precise changes to people's genes. This technology has shown promise in treating genetic disorders like β-thalassemia in both research and medical settings. Gene editing helps bone marrow transplants work better and not cause complications, so it could be a great treatment for people with β-thalassemia who need blood transfusions.[20] Haemopoietic stem cell transplantation should be offered to thalassemia patients (and families) at an early age, or before complications due to iron overload have developed if an HLA identical sibling is available. Either bone marrow or line blood from HLA indistinguishable kin can be

utilized. A matched unrelated donor can be selected as a haemopoietic stem cell transplant donor for thalassemia, provided that high compatibility criteria.[21]

4. Complications:

4.1 Iron overload

Getting regular blood transfusions can cause the body to have too much iron, which is a common problem for people with thalassemia. This extra iron can harm the liver, heart, and endocrine system. Infection: Individuals with thalassemia have high risk of infection and this is harmful for body organs.[22]

4.2 Bone deformities

This illness affects how the body grows. Afterwards, it could be observed in patients with thalassemia. OR after that, it might be seen in people with thalassemia. Most of the time, you can see the skull bone. The bones in the face and the skull get thicker, and this can cause problems with how the bones grow.[23]

4.3 Enlarged spleen

Spleen enlargements have many infectious, viral and bacterial causes, and is incidental due to bugs in the blood flow and liver failures. When the liver is swollen, it will press on the spleen. Thalassemia is a sickness that can make your spleen get bigger.[24]

4.4 Slowed growth rates

Thalassemia induced Anemia can both slow a child's growth and delay puberty. Normal growth of beta thalassemia children during the first 10 years of life depends upon the maintenance of hemoglobin levels above 8.5 g/dl. During this period of the child’s life hypoxia may be the main factor retarding growth.[25]

4.5 Impacts of Awareness and advocacy on Thalassemia patients:

Expanded mindfulness campaigns help teach people and healthcare suppliers approximately thalassemia side effects, empowering early location through screening programs. Early conclusion permits for provoke administration and decreases the hazard of complications such as organ harm and press over-burden. Concurring to a consider distributed within the diary

Hemoglobin, early discovery essentially moves forward treatment results and generally guess for thalassemia patients.[26] Mindfulness activities frequently address the psychosocial needs of thalassemia patients and their families, diminishing shame and giving back systems. Promotion endeavors can impact healthcare arrangements pointed at making strides get to reasonable treatment, counting subsidized pharmaceutical and healthcare administrations for thalassemia patients. Moreover, backing enables patients and their families to effectively take an interest in decision-making forms concerning their healthcare needs. A consider distributed in Wellbeing Arrangement and Arranging highlights the part of quiet promotion in forming approach mediations for thalassemia anticipation and management.[27]

5. Literature review:

In reaction to the elemental move that has been taking put within the way unremitting infections are seen and overseen and the increasingly set up part of patients as rise to accomplices within the administration of their condition, the Thalassemia International Federation (TIF) has undertaken the design and development of a comprehensive online Expert Patients' Program (EPP) for patients with thalassemia. Focusing particularly on β-thalassemia, the most severe form of thalassemia, the goal of the program is to develop patients' disease-related knowledge and self-care skills and enable them to co-manage their disease in a meaningful partnership with their treating physicians. An important goal of this course is to empower patients to advocate for the improvement of national treatment services in every affected country. This article has three main goals which are, Connect TIF's EPP with the goals and results of other EPPs that are written about in the literature. Explain why TIF's EPP is different based on how people learn and forget things, and what scientists recommend of Human Computer Interaction (HCI) and Technology-Assisted Learning (TEL), and Relay the objectives of TIF's EPP and the intended international impact in relation to TIF's mission.[28]

In the last few decades, patients with thalassemia have been surviving better in wealthy countries. Having access to safe blood transfusions, medicine that removes excess iron, new ways to check iron levels in the body, and other improvements in the care of thalassemia patients have all helped patients get better. This may not be true for patients born in countries with limited resources. Unfortunately, in these countries where thalassemia is very common, there are still big worries about infections being passed through blood transfusions. Also, it may be hard

for people to get oral iron chelators and MRI scans to check their iron levels. This can make it difficult for people to follow their treatment plan and properly manage their iron levels. All these limitations will lead to reduced survival and increased thalassemia-related complications and subsequently will affect the patient's quality of life. In nations with limited financial resources, it is essential to enhance healthcare and utilize initiatives such as public education and screening programs to combat the burden of disease. This can help people get the right help and support they need. There are many ways to make things better by working together with rich countries and poor countries. Future studies should concentrate on how well patients feel as a result of their care.[29]

β-thalassemia (BT) is a genetic blood disease transmitted genetically and caused by a mutation in the gene. In the most severe forms, blood transfusion is necessary for the survival of the patients. BT is not widely distributed, but it is commonly found in the Mediterranean, Middle East, Central Asia, India, South America, and North Africa. - Although a cure for this disease has not been discovered, promising results are being seen with new treatments and gene therapies. The study explores the ways in which BT can influence patients' lives within different social environments. This article explores the comparison between thalassemic patients and healthy population in their social, health related and school functioning activities. The negative results highlight the significance of the introduction of suitable programs by healthcare providers, counsellors, and education authorities to provide psychosocial support and improve academic performance. In addition, genetic counselling and intervention programs would positively impact the lives of patients with thalassemia.[30]

6. Material & Method:

In this chapter we discussed research methods including (Type of research, Population, Sample Size, Sampling Scheme, Research Design, Data Collection Tool, Description of Data Collection Tool, Data Analysis, Software, Limitations of Study), and applied descriptive statistics, multivariate analysis of variances and correlation tests.

6.1 Type of research:

Methodology plays an important role in applied research. To achieve objectives and find out their answer to a research question always used an appropriate research method. We used

quantitative research methodology for our research because it is a structured predetermined methodology and reliable for our objectives and it explain clearly our opinion and nature of issue. According to this methodology our results are necessary.

6.2 Location:

Our location where we performed this research was Wazirabad and Gujrat city (Punjab, Pakistan).

6.3 Population:

In this study we have studied to investigate COMPLICATIONS AND MANAGEMENT OF THALASEMIA AND THALSEMIA INDUCED ANEMIA IN LIFE OF THALSEMIC PATIENT AND IMPACT OF AWARENESS IN GENERAL POPULATION. Our target population was thalassemic patients for investigating complication and management of thalassemia and for investigation of level of awareness about thalassemia our population was general people.

6.4 Sample:

During this research, data was collected from patients linked with the Sundus Foundation Wazirabad and Gujrat (Pakistan), a well-established organization dedicated to supporting individuals with thalassemia and other blood disorders. To collect data about awareness of thalassemia our sample was university students and teachers and other staff of university of Chenab (Gujrat), and their families.

6.5 Sample size:

The sample size for awareness about thalassemia was approximately 310 and sample size for complications of thalassemic patients was 100.

6.6 Data collection tool:

Data collection tools are the way to gather and analyze information in a methodical way. This process allows one to respond to specific research questions, test hypotheses, and assess results. Our data collecting tool was Questionnaire.

6.7 Data analysis:

Data was scored according to the standard procedure and for further analysis frequency distribution method was applied through statistical package for social sciences (SPSS. 21).

6.8 Questionnaire:

We conducted a method of questionnaire for collecting the data because it is a structured approach. We launched 2 questionnaires, one to investigate the complications and management of thalassemia. And the other one was to investigate how much awareness is present in general of people about thalassemia.

Table1: Questionnaire about complications and management of thalassemic patients:

Questionnaire about complications and management of thalassemic patients:

We are doing an investigation on COMPLICATIONS AND MANAGEMENT OF THALASSEMIA AND THAL SEMIA INDUCED ANEMIA IN LIFE OF THALSENIC PATIENT AND IMPACT OF AWARENESS IN GENERAL POPULATION.

Please express your views freely. All the information you provide will be confidential and will be used only for research purposes. Thanks in advance for your participation.

Section -A

Demographic Information

Sr.	Question	Option A	Option B	Option C	Option D
1.	**Age**	Below 18	18 to 24	24 to 35	Above 35
2.	**Gender**	Male	Female		
3.	**Marital Status**	Single	Married	Divorced	
4.	**Area of residence**	Rural	Urban		
5.	**Years suffering thalassemia**				

Section -B

Use the following Options: **YES or NO**

General health and medical history

Sr.	Statements	Yes/No
1.	Do you feel your energy level is low?	
2.	Do you often feel fatigued, even after getting a full night's sleep?	
3.	Have you experienced unexplained weight loss recently?	
4.	Have u done your thalassemia test?	
5.	Have you ever had a blood transfusion?	
6.	Do you have a family history of anemia or thalassemia?	
7.	Have you ever been told that you have low hemoglobin levels?	

Lifestyles and Habits

Sr.	Statements	Yes/No
1.	Do you have a history of heavy alcohol consumption?	
2.	Have you ever been diagnosed with any type of anemia? If yes, which type?	
3.	How often do you consume foods rich in iron, such as spinach, cereals, or red meat?	
4.	Do you have a history of exposure to toxic chemicals or heavy metals?	

Women's Health: (For female participants)

Sr.	Statements	Yes/No

1.	Have you noticed any changes in your menstrual cycle, such as heavy bleeding or irregular periods?	

Blood Disorders

Sr.	**Statements**	**Yes/No**
1.	Have you ever been diagnosed with thalassemia?	
2.	Have you ever received treatment for anemia or thalassemia?	

Cardiovascular and respiratory health

Sr.	**Statements**	**Yes/No**
1.	Have u noticed any changes in your breathing, especially while lying flat?	
2.	Have u noticed any changes in your chest or any heart related problem?	

Digestive Health

Sr.	**Statements**	**Yes/No**
1.	Have u noticed any changes in your GIT? Such as, blood in stool, or GIT bleeding?	
2.	Have u experienced difficulties swallowing or a feeling of food getting stuck in your throat?	

Neurological and Sensory Health

Sr.	**Statements**	**Yes/No**
1.	Do you have difficulty sleeping or insomnia?	

2.	Do you experience frequent headaches or dizziness?	
3.	Have u noticed any changes in your sense of smell or taste or hearing or ringing in your ears?	

Other Medical Conditions

Sr.	**Statements**	**Yes/No**
1.	Do you have a history of chronic illness or kidney disease or autoimmune disorder?	
2.	Do u have a history of chronic infection such as, tuberculosis or HIV/AIDS?	

Environmental and exposure history

Sr.	**Statements**	**Yes/No**
1.	Have u noticed any changes in your skin or nails, texture such as paleness or yellowing?	

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Table No:2 Questionnaire for Awareness about thalassemia

Questionnaire for Awareness about thalassemia:

We are doing an investigation on COMPLICATIONS AND MANAGEMENT OF THALASSEMIA AND THAL SEMIA INDUCED ANEMIA IN LIFE OF THALSENIC PATIENT AND IMPACT OF AWARENESS IN GENERAL POPULATION.

Please express your views freely. All the information you provide will be confidential and will be used only for research purposes. Thanks in advance for your participation.

Section -A

Demographic Information

Sr.	Question	Option A	Option B	Option C	Option D
1.	**Age**	Below 18	18 to 24	24 to 35	Above 35
2.	**Gender**	Male	Female		
4.	**Area of residence**	Rural	Urban		

Awareness about thalassemia:

Sr.	Statements	Yes/No
1.	Do you know what thalassemia is?	
2.	Have u done your thalassemia test?	
3.	Do you know about world thalassemia day?	
4.	Do you agree to conduct your thalassemia test?	
5.	Do you want to donate blood to thalassemia patients?	
6.	Have you ever observed any symptom of thalassemia (fatigue, pale skin, low Hb level etc)?	
7.	Have you any family history of thalassemia?	

8.	Do you Know thalassemia is not curable but manageable?
9.	Do you aware of carrier status of thalassemia?
10.	Do you agree that everyone should conduct thalassemia test before marriage?
11.	Do you know thalassemia is a genetic disorder?
12.	Have u ever participated in any awareness campaigns related to thalassemia?
13.	Do you think more education about thalassemia is needed in educational institutes?
14.	Do you know about the complications related to thalassemia?
15.	Will u be the part of our thalassemia awareness campaign?

7. Results and Discussion

7.1 Results about awareness of thalassemia:

We collected data from 306 respondents, but majority of respondents lie between ages of 19 to 23. In 306 respondents 75.8% were those who have knowledge that what is thalassemia, only 21.9% are those who have done their thalassemia test. 73.9% are those who wanted to conduct their thalassemia test.

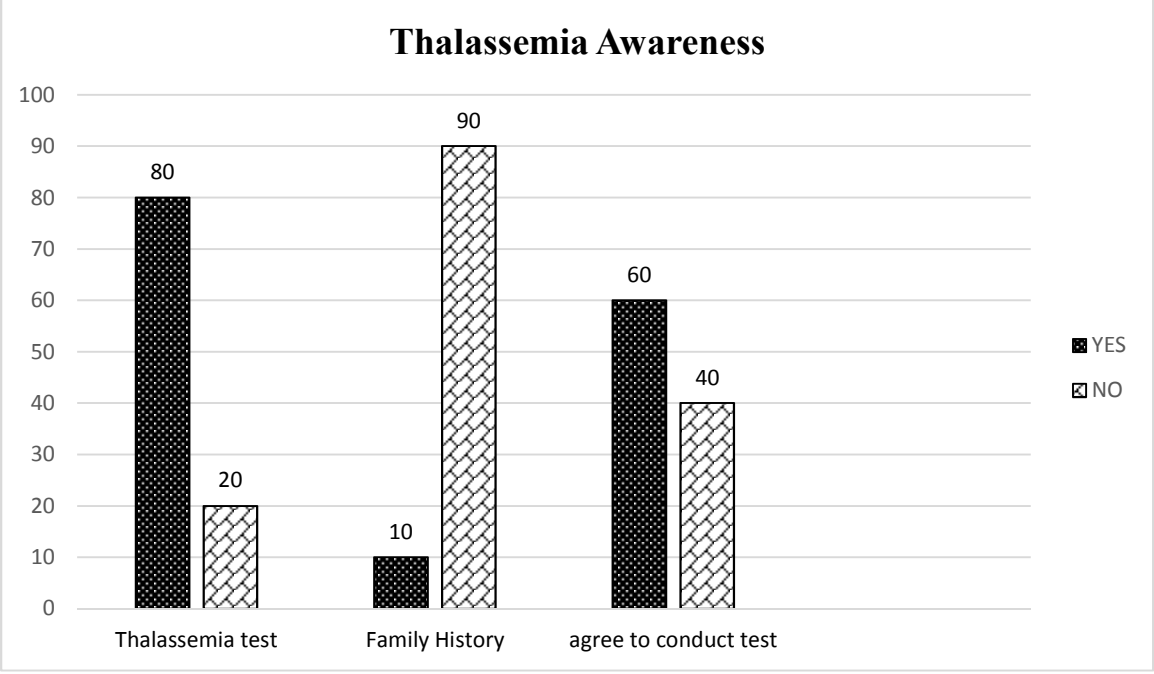

Figure 02: percentage respondent who was aware of Thalassemia

In 306 respondents 73.5% are those who have not ever observed any symptom of thalassemia, 10.8% are those who have family history of thalassemia. In our respondents 73.2% respondents are those who agreed to conduct thalassemia test before marriage and 56.9% are those who have information that thalassemia is a genetic disorder, 86.9% are those who thought that education about thalassemia is needed in educational institutes, 53.3% are those who don't know about complications of thalassemia.

7.2 Results related to complications of thalassemia:

The data was collected from 100 respondents which was suffering from thalassemia. There are 44 male students, and 56 female patients respond the answers out of 100 patients. The average age of the patient is below 20. Among these patients 78% thalassemia patients feel low energy level. Those patients who feel fatigued even after a full night's sleep are 62%, and 28% of thalassemia patients have recently experienced unexplained weight loss. All the thalassemia patients receive blood transfusion and other treatments. 76% patients have a family history of thalassemia or anemia. 68% patients face the complication of low Hemoglobin level. There were 56 female patients among them there were 25% women who face menstrual issues. 2% thalassemia patients have a history of alcohol consumption.

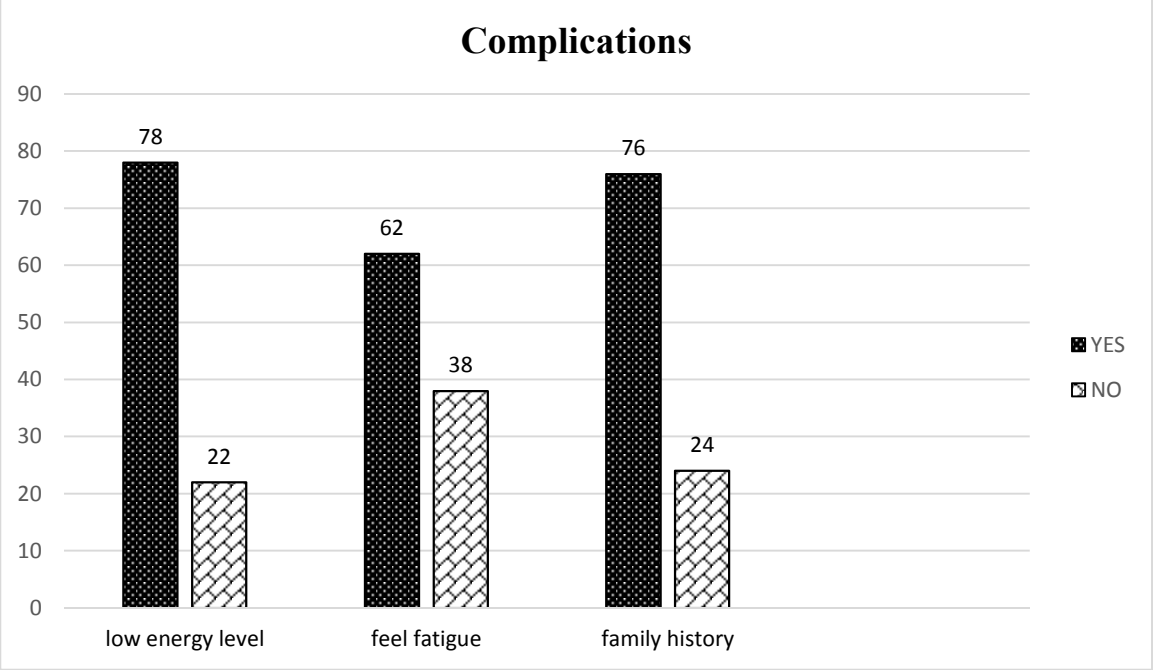

Figure 03: percentage respondent who suffered with specific Complication

60% of thalassemia patients also had anemia, 13% of patients include iron-rich foods in their diet, 33% of patients have a past history of exposure to toxic chemicals or heavy metals, 29% of patients experience breathing difficulties, 12% of patients encounter changes in chest or heart-related, 29% of thalassemia patients experience gastrointestinal (GIT) changes like blood in stool, black stool, or GIT bleeding, 29% of patients experience difficulty swallowing, 58% of thalassemia patients experience difficulties with sleep or insomnia, 20% of patients experience headaches or dizziness, 15% of patients exhibit alterations in their senses,

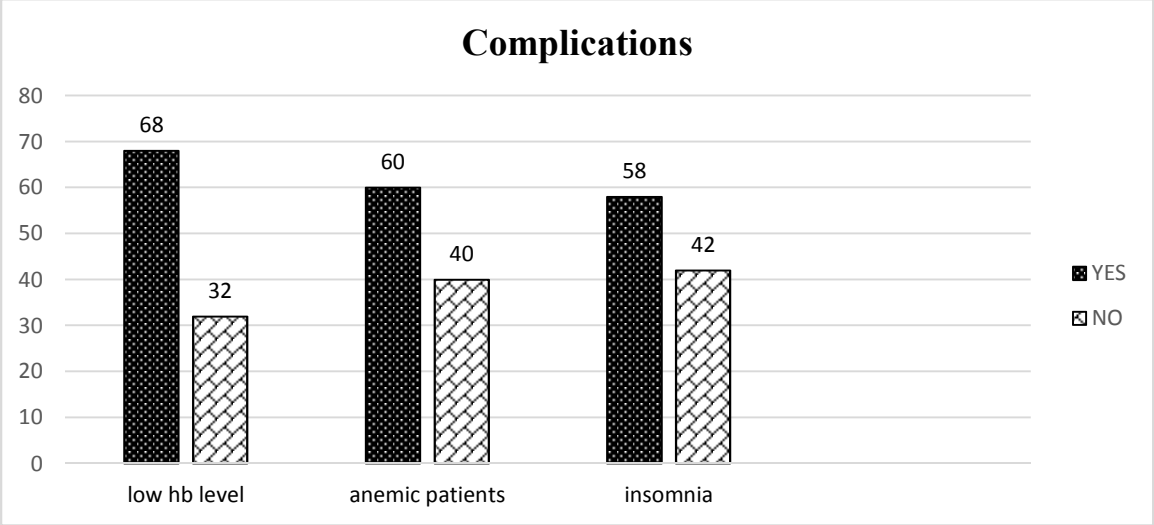

Figure 04: percentage respondent who suffered with specific Complication

8% of patients have a history of chronic illnesses like kidney disease or autoimmune disorders, 34% of patients experience changes in their skin or nails, including alterations in texture such as paleness or yellowing, 12% of patients suffer from liver diseases, only 2% of patients have undergone radiation or chemotherapy treatment.

8. Conclusion

8.1 Conclusion about Awareness of thalassemia:

We collected the data from 306 respondents in which females are in majority. And in these 306 respondents only 21.9% are those who have done their thalassemia test but 78.1% are those who don't have done their thalassemia test. By analyzing other variables, it is concluded

that still now awareness about thalassemia is too much less so we should spread awareness among people we should conduct seminars on thalassemia to minimize the ratio of thalassemia patients.

8.2 Conclusion about Complications of Thalassemia:

The test comprises of 44 male and 56 female thalassemia patients, with an normal age underneath 20. About half of the patients (49%) weigh less than 40kg. The dominant parts of patients (84%) are single, whereas a little rate is hitched (14%) or separated (2%). All patients have been analyzed with thalassemia since birth and have experienced blood transfusions. A basic degree of patients (76%) has a family history of thalassemia. A gigantic divide of patients (78%) report feeling moo essentialness levels, while a more diminutive rate (22%) does not include this sign. More than half of the patients (62%) experience fatigue even after a full night's sleep. A notable percentage (28%) has recently experienced unexplained weight loss. Many patients (68%) face the complication of low hemoglobin levels. Over a quarter of female patients (25%) report menstrual issues such as heavy bleeding or irregular periods. All patients are getting medications for thalassemia. As it was a little division of patients (2%) have a history of liquor utilization. A larger part of patients (60%) has iron deficiency, showing a common comorbidity. The critical extent of patients (33%) has a history of presentation to harmful chemicals or overwhelming metals. Breathing challenges, gastrointestinal changes, trouble gulping, and rest issues are moreover detailed among the persistent populace, but to shifting degrees. Inveterate ailments are generally unprecedented among the patients (8%). Incessant contaminations, such as tuberculosis or HIV/AIDS, are detailed by a little rate of patients (11%). Skin and nail changes, as well as liver illness or hepatitis, are watched in a parcel of the persistent populace. Radiation or chemotherapy medications are uncommon among thalassemia patients (2%).

9. Discussion:

All the results regarding awareness about thalassemia showed that a high percentage of respondents knows that what is thalassemia, but only 50% respondents knows that it is a genetic disorder and its complications. Most of the respondents know the importance of conducting thalassemia test and agree everyone should conduct thalassemia test, but less than 25% patients

have conducted this test. And an enormous number of respondents are those who think that thalassemia education is needed in educational institutes. So, seminars and symposiums should be conducted in school, colleges and universities about thalassemia which can help in cessation of new thalassemia cases. In the results of complications of thalassemia showed that all the thalassemic patients receives blood transfusions and medications. Patients are suffering since childhood because it is transmitted genetically. As described above it also causes anemia due to the low level of Hb. All the patients receive blood transfusions, they may face blood disorders. It also causes other complications like fatigue, sleep disorders, GIT disorders, weight loss, and other chronic infections. And it causes excess iron to store in tissues, which causes iron- induced organ damage. So, patients are also treated with iron chelation drugs. Patients face different complications so patients should be monitored in case of appearance of such problems. Health care providers can overcome such problems very efficiently and patient quality of life can be improved easily. This improvement can be beneficial for thalassemic patients. By doing so, patients will feel better and its trust on health sector will become more and more.

10. Future Implications:

The research which we conduct is beneficial for the Thalassemia patients and their families, Healthcare professionals, including physicians, nurses, and allied health professionals, Researchers and academics in the field of thalassemia. To those Policy makers and advocacy groups working in healthcare policy, public health, and patient advocacy can use your research to inform policy development, resource allocation, and advocacy efforts related to thalassemia.

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