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Sociological Analysis of the patients with genetic disorder Thalassemia: A Study of Ward no 25 for Thalassemia patients in PGIMS Rohtak

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ABSTRACT

This research paper addresses the relevance of Parsons' concept 'sick role' to the experience of illness through a genetic disorder Thalassemia in contemporary society, which suggests that the increasing predominance of this chronic disorder changes the temporal structure of the society. This has important implications for structure of social expectations and obligations associated with the 'sick role'.Thalassemia is a genetic disorder and 10% of the world's total Thalassemic patients are found in India. The concern is that one out of every 30 children is born with Thalassemia trait/carrier of mutated gene.With specific application to a group of people those living relatively long term with a genetic disorder whichever transmitted through parents to their off-springs. Approximately 20% of the world population carries alpha and beta Thalassemia. India is also one of the countries of the world which is severely affected by thalassemia disorder as there are 40 million Thalassemia careers in India and 1 lakh thalassemia major patients who have to depend on blood transfusions on regular basis. 3000 children in the world die every year due to uncontrolled iron overload of the age at 10 to 20. The child with the affected gene can be prevented from being born with Chronic Vellus Sampling during 11-13 month of pregnancy.

1. Introduction

Humans are an integral part of the society as their action and interaction determined the structure of the society.

Any society can function well only if, when parts contribute in its development. If an important part of the younger generation of a society cannot contribute to the development of the society due to its inadequacy, then how society can sustain the goal of development? The eminent psychologist rightly said that man's behavior is influenced by two forces as heredity and environment. The biological characteristics are transmitted to children by their parents. Heredity traits are intrinsic when the association of two parent cells, that come together when a male sperm fertilizes a female egg. So, the chromosomes and genes of parents determined the characteristic of their children and Beta-thalassemia are caused by point mutations or deletions in the beta globin gene on chromosome 11.[1]

Thalassemia is derived from the amalgamation of two Greek words, Thalassa (Mediterranean Sea) and the later meaning is "Weak Blood", which Professor Cooley, the American pediatrics, was the first whoever explained the symptoms and characteristics of this genetic disorder[2]. Thalassemia is a genetic blood disorder which is passed on parents to children. Due to lack of awareness 0.44 per 1,000 children born in the worldwide suffer from thalassemia major[3]. In Indian continental 10% of total world Thalassemia population is suffering from this chronic disease[4]. In the absence of adequate knowledge about this disorder, parents couldn't know their Thalassemia status and after the birth of Thalassemia major child, they come to know about this genetic disorder. Gynecologists furthermore don't ask to diagnose the disease, due to which children are being born with thalassemic genes. If gynecologist writes to test for HB Electrophoresis or HBA2 test during pregnancy and if pregnant woman is found to have thalassemia trait, Chronic Vellus Samplingcan be done to screenwhether the child is suffering from thalassemia or not, between 11 and 13 weeks of pregnancy.[5]

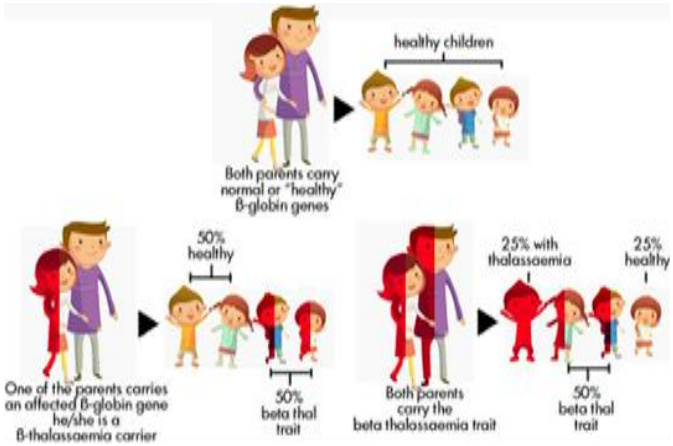
[1]Galanello Renzo, OrigaRaffaella. Beta- Thalassemia. Orphanet Journal of Rare Diseases. 2010;5:11.www.ncbi.nlm.nih.gov/pmc/articles/PMC2893117/

[2]Cooley TB, Lee P., A Series Of Cases Of Splenomegaly In Children With Anemia And Peculiar Bone Changes, Trans Am PediatrSoc 1925, 37:29-30

[3]Rund D.,Rachmilewitz E.,Beta-Thalassemia.N Engl J Med. 2005;353:1135-46. DOI: 10.1056/NEJMra050436

[4]Malakar R., A Review on: B- Thalassemia. World Journal of Pharmaceutical Research.Vol. 5.Issue 6.2016; ISSN 2277-7105. 432-445.

[5]Colah Roshan,Italia K.,GorakshakarAjit.Burden Of Thalassemia In India:Tha Road Map For Control.Pediatric Hematology Oncology Journal. Volume 2.Issue 4.2017:79-84



Since 1925 when American pediatrician Thomas Cooley first described about Thalassemia, our level of information has increased so much that we can crush the disease nip in the bud. Due to this fatal disease, 1 child of every 45 minutes and 10000 children in one consecutive year are being born with Thalassemia affected gene.

Hemoglobin is made up of two words heme and globin, the globin is made up of four proteins, two of which are called beta chains and two parts similarly called alpha chains. Thalassemia major child appears to be healthy due to hemoglobin F at birth (in which two alpha and two gamma chains are found), but within the first month of the baby's birth, anemia starts slowly and gradually takes on serious form. Due to lack of blood, fever, diarrhea or other problems, child's growth and development stops.[6]

Normal hemoglobin called HB A consists of four protein chain –two alphaglobin and two betaglobin. The two major types of Thalassemia Alpha and Beta are named after defects in these protein chains[7]. Two genes (one from each parent) are needed to make enough Beta protein. Beta Thalassemia occurs if one or both genes are mutated[8].

Types of Beta Thalassemia: - It can be bifurcated into three types...

Minor Thalassemia, (heterozygous)-Thalassemia minor has only one copy of the affected gene associated with one perfectly normal beta chain gene. However person with Thalassemia minor have a normal blood iron level unless they are iron deficient for other reasons.

Intermedia Thalassemia (Non Transfusion dependent thalassemic) - in this stage symptoms are found less and requires less blood or after five to six years.

Major Thalassemia (Homozygous Cooley's anemia) -the most dangerous condition in which the symptoms of disease begin to appear a few months after birth. The child born with Thalassemia major has two affected genes and no normal beta- chain gene. The size of RBC in affected person usually have smaller and survival rate of Red blood cells is 15 to 20 days comparison to normal man which RBC survive 120 days[9] .Thereby, Due to this there is a lack of blood in the patient's body and he has to resorted blood transfusion after every three weeks. By which the iron element gets accumulated (Iron Overload) in individual body and many parts of the body can be affected due to overload such as liver, kidney and heart and condition of reversal damage usually known as cirrhosis occurred in which DNA of the liver cell damaged and increased the risk of liver cancer.Low bone mineral density causes weakness in bones, which increases the risk of osteoporosis as well as increases the risk of bone fracture after 20 years of age[10]. Most of the thalassemia major patient born in under develop and low income countries and patient has to resort iron chelation therapy which is very painful and expensive too[11].Due to this disease, 25,000 Thalassemia patients died in 2013 in the whole world.[12] Thalassemia is a genetic disorder that is inherited in the patient and it is rapidly spreading due to the immigration pattern

[6]Weatherall J. D.,The Role Of The Inherited Disorders of Hemoglobin,The First "Molecular Diseases,"In The future Of Human Genetics.1-28. www.annualreviews.org/doi/pdf/10.1146/annurev-genom-091212-153500

[7]Weatherall DJ. Thalassemia as a global health problem: Recent progress toward its control in the developing countries. Ann NY AcadSci 1202:2010; 17–23

[8]https://www.medicinenet.com/beta_thalassemia/article.htm#what_is_beta_thalassemia

[9]Nitu Nigam, Sanjay Nigam, Monica Agarwal, Prithvi Kumar Singh. β-Thalassemia: from clinical symptoms to the management. International Journal of Contemporary Medical Research 2017;4(5):1066-1070

[10]Lampropoulou-Adamidou K.,Tournis S.,Triantafyllopoulos.A Typical femoral fracture in a beta-thalassemia major patient with previous bisphosphonate use:case report and a review of the literature. Journal of musculoskeletal and neuronal interactions.2016; 16(1):75-78.

[11]Modell B.,Darlison M. Global Epidemiology of Haemoglobin Disorders and Derived Service Indicators. Bulletin of the World Health Organization. Volume 86.2008:417-496.

[12]Sharma D. C. et al., Overview on Thalassemia: A Review Article. Medico Research Chronicles. 2017, 4 (3), 325-337

and population flows in the United States, which causes blood transfusions in anemic patients. Bone marrow transplantation is an only treatment, but it is very expensive and success rate is very low. Throughout the 13 to 15 weeks of pregnancy, this disease can be prevented by detecting this gene in the whole world.[13]

2. Methodology:

Present study is descriptive in nature which aims to find out information about Thalassemia disorder and provide an insight into understanding the problems faced by the person with this disorder. Therefore for this purpose, data has been collected from Thalassemia major patients through Interview schedule technique, whoever had been came for blood transfusions at Rohtak Medical PGI Ward no. 25. An advance statics techniques like SPSS to present data in simple and comparable form.

3. Results and Discussion:

Table 1

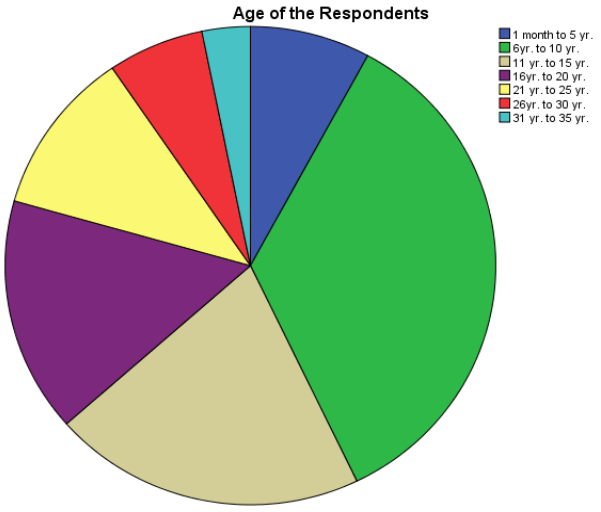
Gender		
	Frequency	Percent
Male	37	58.7
Female	26	41.3
Total	63	100.0

In the above mentioned table, Data from 63 Thalassemia patients, including 37 males and 26 females from Haryana and Uttar Pradesh, gathered from Rohtak PGI Thalassemia ward.

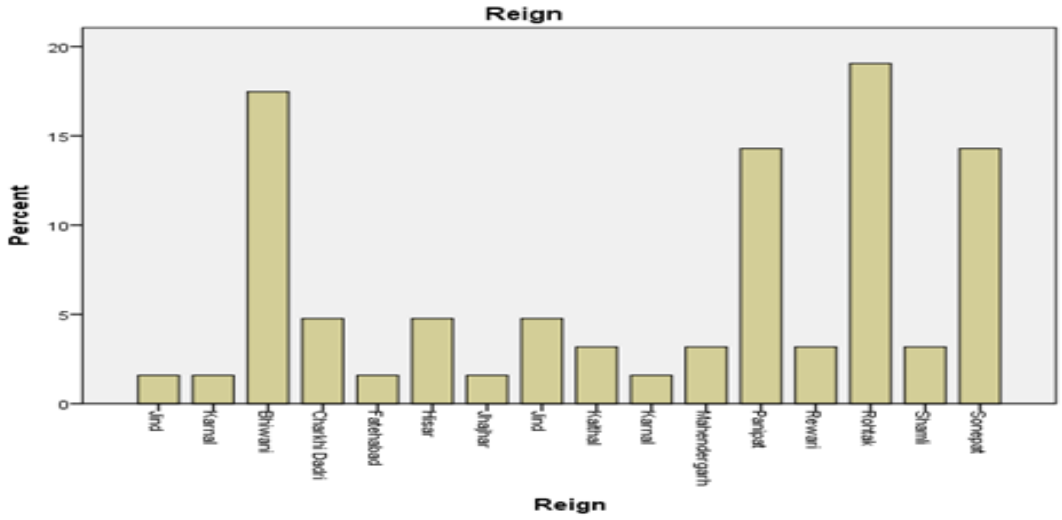
As per the table 2, we get Thalassemic patients from 3 months to 35 years. Research comprise, Thalassemic patients from 3 months to 35 years which included 3 month to 5 years, 6- 10 years, 11-15 years, 16-20 years, 21- 25 years and the percentage of respondents was 7.9%, 34.9%, 20.6% , 15.9% respectively. We found two patients who take regularly blood transfusion on every 20 days from 35 years.

Table2

Age of the Respondents		
Age of the Respondents	Frequency	Percent
3 month to 5 yr.	5	7.9
6yr. to 10 yr.	22	34.9
11 yr. to 15 yr.	13	20.6
16yr. to 20 yr.	10	15.9
21 yr. to 25 yr.	7	11.1
26yr. to 30 yr.	4	6.3
31 yr. to 35 yr.	2	3.2
Total	63	100.0



[13]Marengo- Rowe A.,TheThalassemias And Related Disorders.BaylUnitv Med Cen Proc.2007 Jan;20(1):27-31



Bar graph from table 3

As per the table majority 65% out of the total Thalassemia patients are from Rohtak (19%), Bhiwani (17.5%), and 14.3% from Panipat and Sonepat respectively. In other districts of Haryana and Uttar Pradesh Patients with Thalassemia have also diagnosed, but the condition of this genetic disorder is worrisome due to the lack of information in the districts of Rohtak, Bhiwani, Panipat and Sonepat.

How long after your birth, your family known the fact that you are Thalassemia Major		
	Frequency	Percent
After 3 to 6 month	28	44.4
After7 to 12 month	13	20.6
After 13 to 18 month	9	14.3
After 19 to 24 month	13	20.6
Total	63	100.0

As per the table 45% parents came to know the fact that their offspring is affected from **Thalassemia major** at the age of 3 to 6 month. It is clear from the table that when the child was one and a half years old, most of the parents knew the fact that their child was suffering from thalassemia major.

From how long have you been taking blood transfusion		
	Frequency	Percent
less than one year	9	14.3
1 to 5 yrs.	15	23.8
6 to 10 yrs.	11	17.5
More than 10 yrs.	28	44.4
Total	63	100.0

When data collected, there were 14.3% Thalassemia patients who were under one year old and were taking blood transfusion. We found Majority 44.4% out of the total were getting BT more than 10 years. We found two patients who take regularly blood transfusion on every 20 days from 35 years.

After how many days do you need to have blood transfusion		
	Frequency	Percent
after 15 days	29	46.0
after 20 days	27	42.9
after 25 days	4	6.3
after 30 days	3	4.8
Total	63	100.0

The surprising thing found by the table that 89% of the total patients found severe urgency to have blood transfusions before 20 days.

Do you know about Nucleic acid amplification test technique		
	Frequency	Percent
yes	28	44.4

no	35	55.6
Total	63	100.0

Nucleic Acid Amplification Test technique is used to detect pathogenic bacteria, viruses or any particular nucleic acid in blood, tissue and urine. NAAT technique detects genetic material as it allows an early diagnosis of a disease in blood, tissue and urine. The detection of antigens needs time for antigens to appear in the bloodstream[14]. Nearly 56% of Thalassemia patients were not aware of NAAT technologybecause the blood examined through the NAAT technology can save Thalassemia patients from diseases like HIV and HCV.

Is NAAT test is helpful to avoid the danger of HIV and HCV		
	Frequency	Percent
yes	40	63.5
no	13	20.6
Do't Know	10	15.9
Total	63	100.0

As per the table majority 64% of the total respondents are in the favour that NAAT technique is helpful to avoid the danger of HIV and HCV.

Is there a facility of bed for every patients where you get blood transfusions?		
	Frequency	Percent
Yes	18	28.6
No	6	9.5
Only one bed in available for two to three patients	39	61.9
Total	63	100.0

As per the table that 62% of total respondents stated that only 1 bed is available for three people.And it was found correct because as many as 15 to 20 patients are given blood transfusions on single day at ward no 25, there only 7 beds are available.

Which procedure you have to follow before blood transfusion		
	Frequency	Percent
HB test for blood	13	20.6
complete blood count	2	3.2
Blood group match	1	1.6
all of the above	47	74.6
Total	63	100.0

Blood sample is taken from the patients, through which their hemoglobin as well as Rhesus factor examined, before blood transfusion by the blood bank officials, after that packed cell valued or washedHCV, HIV and HBsAg negative blood is transfused to patients as prescribed by the doctors.

The blood whichever you got from PGI is completely HIV,HCV,HBsAg negative					
	Frequency	Percent	**If no, then why**	Frequency	Percent
yes	24	38.1	NAAT facility is not available at Rohtak PGI	37	58.7
not completely	39	61.9	not applicable	19	30.2
			I was not affected HCV earlier	7	11.1
Total	63	100.0	Total	63	100.0

When the thalassemia patients were asked if they were givenHIV, HCV, HBsAg negative blood, then 62% of the respondents stated that not completely as NAAT technology is not available in Rohtak medical and **11% of the respondents replied that they were not suffering from HCV before they started blood transfusion.**

[14]E.A. Mothershed, A.M. Whitney. Nucleic Acid-Basedmethods For ThedetectionofBacterial Pathogens: Present And Future Considerations For The Clinical Laboratory. ClinicaChimicaActa 363 (2006) 206 – 220

When you leave your house for the process of blood transfusions and when you reach home, how much time does it take the whole procedure		
	Frequency	Percent
9 to 10 hours	23	36.5
10 to 12 hours	16	25.4
12 to 14 hours	18	28.6
14 to 16 hours	6	9.5
Total	63	100.0

It takes 9-10 hours to get blood transfusions in patients living in Rohtak and vicinity areas.But people coming from remote areas such as Rewari, Mahendragarh and Bhiwani, the whole process take 14 to 16 hours. The patients coming from Panipat and Sonepat take 12 to 14 hours. Thus all day of blood transfusions goes out in this way for the Thalassemia patients.

What is ferritin level in your body			What precautions do you follow to keep your free level low		
	Frequency	Percent		Frequency	Percent
Below 1000 ng/ml (nanograms per milliliter of blood)	6	9.5	By not consuming iron-grained vegetables and fruits	2	3.2
Between1000 to 3000 ng/ml (nanograms per milliliter of blood)	33	52.4	to take special drugs which helps to removal excess iron from the body of TH patient	14	22.2
Between 3000 to 5000 ng/ml (nanograms per milliliter of blood)	18	28.6	consuming more citrus fruits	1	1.6
`More than 5000 ng/ml (nanograms per milliliter of blood)	6	9.5	all of the above	46	73.0
Total	63	100.0	Total	63	100.0

A ferritin test helps to measuresyour doctor that how much iron your body is storing. Ferritin is a blood cell protein that contains iron. In general, normal ferritin levels range from 12-300 Nano grams per milliliter of blood (ng/mL) for males and 12-150 ng/mL for females.[15]Majority of the patients (52%) found Ferritin Level 1000 to 3000 ng/ml, patients (28.6% of the total thalassemic patients found their Ferritin Level in between 3000 to 5000 ng/ml and rest of the 6% found their ferritin level below 1000 ng/ml and More than 5000 ng/ml respectively.In this way, these patients have to resort to Iron Chelation therapy to remove more ferritin from their body than necessary.

Majority of the respondents (73%) keep their ferritin level low by not consuming iron-grained vegetables and fruits, to take special drugs e.g. (Desirox tablet / kelfer capsule)which helps to removal excess iron from the body of Thalassemia patient and by consuming more citrus fruits.

Are you being offered free medicine by hospital staff					
	Frequency	Percent	If yes, then name of the medicine	Frequency	Percent
yes	63	100.0	Desirox tablet/ kelfer	8	12.7
			Calcium tablet and folic acid	3	4.8
			all of the above	37	58.7
			both 1 and 2	15	23.8
			Total	63	100.0

As per the table it is commendable effort to provide free medicine to thalassemia patients at PGI Rohtak for Iron Chelation therapy to remove more ferritin from their body that helps people to live quality lives.

As per the table majority (59%) of the respondents stated that medicine like Desirox tablet/ kelfer, Calcium tablet and folic acid are provided to Thalassemia patients by ward no 25 at PGI Rohtak.

Is regular blood test is done by hospital staff to keep thalassemia patients healthy					
	Frequency	Percent	If yes, then name of these tests	Frequency	Percent
yes	59	93.7	CBC, KFT, LFT, HCV, HIV, HBsAg	60	95.2
no	4	6.3	FERRITIN	3	4.8
Total	63	100.0	Total	63	100.0

As per the table majority 93% of the total respondent stated that their hemoglobin as well as Rhesus factor examined, before blood transfusion by the blood bank officials and after every three months they are tested for HBsAg, CBC, HCV, HIV, KFT, LFT.

[15]Stoppler, M. C. and Davis, C. P. (2018). “Ferritin Blood Test”
https://www.medicinenet.com/ferritin_blood_test/article.htm#ferritin_blood_test_facts

Do your other siblings suffer from this genetic disorder		
	Frequency	Percent
yes	7	11.1
no	56	88.9
Total	63	100.0

According to the 89% respondents none of their brother or sister is not suffering from this genetic disease after getting sufficient knowledge about this genetic disorderBut we found 7 patients, whose brother or sister also suffered from thalassemia due to lack of full knowledge of their parents. Their parents took their genetic counseling before planning another child and after that, during the 11 to 13 months of pregnancy, they went for chronic vellus sampling (CVS) to ensured that their would be child is not suffering from thalassemia genes.[16]

How many Thalassemia Major patients is known by you, who have undergone bone marrow transplantation					
	Frequency	Percent	**In which age BMT is most successful**	Frequency	Percent
none	45	71.4	Between 1- 5 yrs.	37	58.7
only 1 to 2 person	14	22.2	Between 6- 10 yrs.	25	39.7
3 to 5 person	2	3.2	More than 15 yrs..	1	1.6
more than 5 person	2	3.2	Total	63	100.0
Total	63	100.0			

Bone marrow is the spongy, fatty tissue inside your bones. It creates the following parts of the blood: red blood cells, which carry oxygen and nutrients throughout the body, white blood cells, which fight infection, platelets, which are responsible for the formation of clots.A bone marrow transplant replaces your damaged stem cells with healthy cells. This helps your body make enough white blood cells, platelets, or red blood cells to avoid infections, bleeding disorders, or anemia.[17] Bone marrow transplantation is the only possible treatment for thalassemia disease, which is expensive, but most patients for bone marrow transplantation do not have a suitable family donor.[18]

As it is clear from the table that 71% of people do not know any such Thalassemia patient who has been undergone bone marrow transplantation.Since it is a difficult, cost-effective and laborious treatment, so few people choose it. According to majority of respondents (98%) that if thalassemia major patient gets a Bone Marrow Transplantation in the age less than 10 years, its success rate increases.

Have you ever been infected with HCV, HIV,HBsAg due to blood transfusions		
	Frequency	Percent
yes	25	39.7
no	38	60.3
Total	63	100.0

The information obtained from the table is surprising because 40% of thalassemia patients are infected with HIV, HCV and HBsAg virus, due to blood transfusions.

Have you ever had to return home without having blood transfusion			What you did in such situation		
	Frequency	Percent		Frequency	Percent
Only once	25	39.7	wait for blood	25	39.7
two to three times	10	15.9	to bring same blood group donor	17	27.0
Many times	9	14.2	have to buy it	2	3.2
Never	19	30.2	Not applicable	19	30.2
Total	63	100.0	Total	63	100.0

The stunning facts came out from the present table that more than 67% of thalassemia major patients either had to wait for blood

[16]Personal interview with Vipin, resident of Rohtak and work as a businessman ,14 July 2018, born in 1983, A Thalassemia Major patient and getting blood transfusion in Rohtak PGI Ward No. 25

[17]Krans, Brian (2016)."Bone Marrow Transplant" https://www.healthline.com/health/bone-marrow-transplant

[18]La Nasa,Giorgio et al. Unrelated Bone Marrow Transplantation for Thalassemia patients: the experience of the Italian bone marrow transplant Group. Ann NY Academic science 1054; 2005:186-195

or bring same blood group donor, 3.2% patients had to buy blood for transfusion. It is obvious that thalassemia patients have to suffer a lot for the arrangements of blood or return without blood transfusion due to non-availability of blood at Rohtak Medical, when they need it severely due to their low hemoglobin.

Are you an active member of a committee that is helping Thalassemia patients			**What is the contribution of these societies to make Thalassemia's patients life with quality.**		
	Frequency	Percent		Frequency	Percent
National thalassemia welfare society	5	7.9	to provide medicine at reasonable rates	1	1.6
Haryana thalassemia welfare society	34	54.0	to organize blood camps on the time of need	2	3.2
both	18	28.6	to arrange a blood checkup camps on the hour of needs	4	6.3
None	6	9.5	all of the above	56	88.9
Total	63	100.0	Total	63	100.0

54% of thalassemia patients found to be associated with the National Thalassemia Welfare Society, 8% are associated with Haryana thalassemia welfare society and 28.6% are associated with both of the societies. When asked about the contribution of these societies to thalassemia patients 89% respondents stated that these societies are very helpful to provide medicine at reasonable rates, to organize blood camps on the time of need and to arrange a blood checkup camps on the hour of needs.In this way, it is clear that working like these societies, helps these patients by going over where the government does not reach.

Does the Thalassemia disorder affect children's education					
	Frequency	Percent	**If yes, then how**	Frequency	Percent
yes	43	68.3	deficiency of blood led to weakness in body which hampers in study and have to take leave twice a month	24	38.1
no	17	27.0	Before education, there is concern about the availability of facilities for the treatment of disease.	8	12.7
Don't know	3	4.8	Both	14	22.2
			Not applicable	17	27.0
Total	63	100.0	Total	63	100.0

According to 69% of the respondents, due to this disorder, the primary, secondary and higher education of patients are also affected.Because of the lack of blood in the body, these people cannot meditate to their studies and at the same time they have to go Rohtak PGI for blood transfusion twice a month[19].13% of the respondents argued that we cannot get good education even after going out,because before education, The only thing that remains in our eyes is whether the basic facilities will be available for treatment or not.[20]

Which facilities are provided by the government for free		
	Frequency	Percent
free bus/train pass	2	3.2
facilities of free blood and medicine	3	4.8
all of the above	58	92.1
Total	63	100.0

It is clear from the given table that 92% of the total respondents have given free bus pass, free medicines and blood transfusions bythe government of Haryana.All these facilities should be made available to them, by the government only at their hometown.

Do you or anyone you know, whoever had faced problem while finding employment due to thalassemia		
	Frequency	Percent
yes	14	22.2
no	49	77.8

[19]Personal interview taken of David's mother on the behalf of David, A six year old boy studying in 1St standard, resident of Panipat,11 September 2018, born in 2012, A Thalassemia Major patient and getting blood transfusion in Rohtak PGI Ward No. 25

[20]Personal interview with Sameeksha Karma, resident of Bhiwani and studying and preparing for NEET exam ,14 July 2018, 23 Yrs. Old, A Thalassemia Major patient and getting blood transfusion in Rohtak PGI Ward No. 25

Total	63	100.0

Respondents around 78% stated that they had no inconvenience in getting jobs due to this disorder.According to them, the only discomfort is that they have to face Rohtak after every 15 days for blood transfusion.Preparation begins for 3 or 4 days before the date of blood transfusion, due to which they cannot make any outdoors program.

Do you know about the Disability Bill 2016			**Do you have disability certificate**		
	Frequency	Percent		Frequency	Percent
yes	36	57.1	yes	22	34.9
no	27	42.9	no	41	65.1
Total	63	100.0	Total	63	100.0

Thalassemia patients have also been included in the Disability Bill passed by the government of India in 2016.But according to the figures from the table, 57% people know about Disability Bill 2016, but only 35% people have been able to make a disability certificate. The reason for behind is either laxity or ignorance of the peoplefor this bill or the complex way of official functioning.

What changes do you feel within a week before the date you have to do blood transfusions			**Things to look for Thalassemia patients to live a quality life**		
	Frequency	Percent		Frequency	Percent
Weakness and fatigue	32	50.8	Regular blood tests and blood transfusion	4	6.3
Both Fever and Weakness	20	31.7	having protein, calcium and vitamin food	5	7.9
			removal of excess iron from body	1	1.6
none	11	17.5	all of the above	53	84.1
Total	63	100.0	Total	63	100.0

As per the table majority 58% of the respondents busted thatthey suffer from weakness and fatigue due to hemoglobin deficiency in the last week and 31.7 % out of total respondents stated that sometimes both from weakness and fever.

According to the majority 84% received from the table, thalassemia patients should have their blood transfusions on a regular date as well as to remove excess iron than required from their body, take regular medicines, whichever the doctor has prescribed for her, should be taken on timeto live a quality life.Along with this, they should also have food containing proteins, calcium and vitamins.

The new medicines whichever prescribed by doctor, has they made life easier for thalassemia patients?		
	Frequency	Percent
Yes	7	11.1
No	7	11.1
New problems occurs with new medicines	15	23.8
Don't know	34	54.0
Total	63	100.0

Some of the patients who are taking some medicines from the Indira Gandhi Hospital and they have their hemoglobin stable or more than10-12 gms, but the Pros and Cons of these medicines has not been exposed, and for this reason, majority of patients avoid these medicine(89%) and hopeful about gene therapy.

You know every aspect of this disorder, and then what message would you like to give to save society from thisgenetic disorder?		
	Frequency	Percent
Thalassemia test should be available for free in all government hospitals	2	3.2
ASHA workers should Encourage one-month pregnant women to investigate their thalassemia status so that their would be children must not suffer from this gene	1	1.6
While making one's ADHAR card or enrolling him in school, he/she should be ask for him/her genetic profile	1	1.6
All of the above	59	93.7
Total	63	100.0

According to the figures from the table, when the respondents were asked, what message you would like to give to society, so that could Thalassemia could not flourish further, the majority stated that the test HBA2/HPLC/HB Electrophoresis for Thalassemia should be available for free in all government hospitals, one-month pregnant women should be encouraged by ASHA workers to investigate their thalassemia status so that their would be children must not suffer from this gene and last but not the leasteveryone should be ask for their genetic profile While making one's ADHAR card or enrolling him in school.

4. Summary and conclusion:

So, in the light of the facts stated above, it may be concluded that 63 people from Haryana and Uttar Pradesh were studied, of which 37 men and 26 women, including 3 months to 35 years of age, patients who have to undergone blood transfusion within 20 days.Most of the patients were from Rohtak 19%, Bhiwani 17%, Panipat and Sonepat with 14%, which reveal the ignorance of the people about this disease in these districts and the failure of the District Hospitals to make the awareness regarding this disease to reach the masses.Thalassemia major disorder can be detected 3 to 6 months after the birth of the child and the said child has to be given lifelong blood every 20 days, which is an annoying process for them and their family members. This is shocking that the blood, which is being offered to the patients, will be completely HCV, HBsAg negative, there is no guarantee of this because 40% of patients found HCV or HBsAg positive, only after starting blood transfusions. The main reason for this is the unavailability of the nucleic acid amplification test in PanditBhagwatDyal Sharma P.G.I.M.S. Rohtak. On average, availability of 1 bed on every 3 patients was found. Thalassemia patients take 10 to 14 hours to get blood transfusions, for which they have to leave their homes early in the morning for Rohtak PGI. The recent roadways strike increased their trouble further. The only solution for the patients to prevent, suffering from this disease is the Bone Marrow Transplantation, and for that govt. assistance of 1000000 rupees as well as auspicious contribution of the National Thalassemia Welfare Society to provide a positive environment for thalassemia patients. However the government has included these patients in the disabled category and they have been given a free bus and train facility for the treatment of this disease. But these children have been discriminated by not providing them free education in the private school as well as disability pension.

There is a need to make some big and fast on this occasion to prevent this disease from growing.

References

1. ColahRoshan,Italia K.,GorakshakarAjit.Burden Of Thalassemia In India:Tha Road Map For Control.Pediatric Hematology Oncology Journal. Volume 2.Issue 4.2017:79-84
2. Cooley TB, Lee P., A Series Of Cases Of Splenomegaly In Children With Anemia And Peculiar Bone Changes, Trans Am PediatrSoc 1925, 37:29-30
3. E.A. Mothershed, A.M. Whitney. Nucleic Acid-Based methods for the detection of Bacterial Pathogens: Present And Future Considerations For The Clinical Laboratory. ClinicaChimicaActa 363 (2006) 206 – 220
4. Galanello Renzo, OrigaRaffaella. Beta- Thalassemia. Orphanet Journal of Rare Diseases. 2010; 5:11. www.ncbi.nlm.nih.gov/pmc/articles/PMC2893117/
5. Krans, Brian (2016)."Bone Marrow Transplant" https://www.healthline.com/health/bone-marrow-transplant
6. Lampropoulou-Adamidou K.,Tournis S.,Triantafyllopoulos.A Typical femoral fracture in a beta-thalassemia major patient with previous bisphosphonate use:case report and a review of the literature. Journal of musculoskeletal and neuronal interactions.2016; 16(1):75-78.
7. La Nasa,Giorgio et al. Unrelated Bone Marrow Transplantation for Thalassemia patients: the experience of the Italian bone marrow transplant Group. Ann NY Academic science 1054; 2005:186-195
8. Malakar,Ramdas. A Review on: B- Thalassemia. World Journal of Pharmaceutical Research.Vol. 5.Issue 6. ISSN 2277-7105. 432-445.
9. Modell B.,Darlison M. Global Epidemiology of Haemoglobin Disorders and Derived Service Indicators. Bulletin of the World Health Organization. Volume 86.2008:417-496.
10. Nitu Nigam, Sanjay Nigam, Monica Agarwal, Prithvi Kumar Singh. β-Thalassemia: from clinical symptoms to the management. International Journal of Contemporary Medical Research 2017;4(5):1066-1070.
11. Personal interview with Vipin, resident of Rohtak and work as a businessman ,14 July 2018, born in 1983, A Thalassemia Major patient and getting blood transfusion in Rohtak PGI Ward No. 25
12. Personal interview taken of David's mother on the behalf of David, A six year old boy studying in 1St standard, resident of Panipat, 11 September 2018, born in 2012, A Thalassemia Major patient and getting blood transfusion in Rohtak PGI Ward No. 25
13. Personal interview with Sameeksha Karma, resident of Bhiwani and studying and preparing for NEET exam ,14 July 2018, 23 Yrs. Old, A Thalassemia Major patient and getting blood transfusion in Rohtak PGI Ward No. 25
14. Rund D.,Rachmilewitz E.,Beta-Thalassemia.N Engl J Med. 2005;353:1135-46. DOI: 10.1056/NEJMra050436
15. Sharma D. C. et al., Overview on Thalassemia: A Review Article. Medico Research Chronicles. 2017, 4 (3), 325-337
16. Stoppler, M. C. and Davis, C. P. (2018). "Ferritin Blood Test" https://www.medicinenet.com/ferritin_blood_test/article.htm#ferritin_blood_test_facts
17. Weatherall J. D.,The Role Of The Inherited Disorders Of Hemoglobin,The First "Molecular Diseases,"In The future Of Human Genetics.1-28. www.annualreviews.org/doi/pdf/10.1146/annurev-genom-091212-153500
18. https://www.medicinenet.com/beta_thalassemia/article.htm#what_is_beta_thalassemia

