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Awareness and practices regarding thalassemia among parents of transfusion dependent beta thalassemia patients registered with Hamza Foundation Peshawar, Pakistan

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***Abstract*---**Background: Thalassemia is a chronic debilitating disease that affects nearly 200 million people worldwide. The beta-thalassemia gene is present in around 3% of the world's population. A caregiver who has good knowledge regarding the disease can not only provide a better quality of care to his/her ward but also contribute in community awareness related to disease. Aims: To determine Awareness and practices regarding thalassemia among parents of

transfusion dependent beta thalassemia Patients register with Hamza foundation Peshawar. Material and Methods: A cross-sectional study was conducted in Hamza Foundation Welfare Thalassemia, Hemophilia Hospital from June 2022 to December 2022. In this study parents (n=150) of patients suffering from beta thalassemia major were included. Information was collected on a questionnaire consisting of all the necessary information regarding thalassemia. All sample were selected using non-probability Convenience sampling technique. Nineteen questions related to knowledge regarding thalassemia and eleven questions related to practices were included. Finally the questionnaires from different parents were analyzed and the result was interpreted. Results: Among the total n=76 (50.7%) were females and n=74 (49.3%) were males. About n=58 (38.7%) of study subjects had knowledge regarding this disease while majority of the patients had no knowledge about the permanent treatment of beta-thalassemia. It was noted that n=141 (94%) of the parents share their foods with children having no hesitation, while only n=20 (13.3%) of the parents received genetic counseling. Conclusion: Parental knowledge about thalassemia was inadequate. It is required to educate not only parents but also general public to create awareness about

***Keywords*---**Hamza Foundation, Cross-sectional study, Thalassemia, beta-Thalassemia, Transfusion. .

Introduction

The word thalassemia comes from the Greek language, Thalassa mean (sea) and haima (blood). Thalassemia is mainly divided into three types: Thalassemia major also known as “Cooley’s Anemia” and “Mediterranean Anemia”, Thalassemia Intermedia and Thalassemia Minor are also called “beta-thalassemia carrier”, “beta-thalassemia trait”. Beta thalassemia is group of autosomal recessive inherited blood disease in which there is decreased or no synthesis of beta globulin chain which lead to decrease hemoglobin in RBCs, reduce red blood cell formation and cause anemia (Galanello *et al.* 2010). Beta thalassemia phenotypes are different, varying from serious transfusion dependent thalassemia major to less serious form of thalassemia intermediate and thalassemia minor. (Danjou *et al.* 2011). The number of copies of the mutated genes that are inherited from an affected parent determines how severe the anemia will manifest clinically. (Galanello and Origa 2010). If both parents are carrier they have 25% of chance to transfer thalassemia major to their children. (Galanello and Origa 2010). The most prevalent hereditary disorder in the world is thalassemia and is kind of monogenic genetic disorder. The beta-thalassemia gene is present in around 3% of the world's population. Thalassemia is most common inherited disease in Pakistan. Over 5000 homozygotes are born each year in Pakistan, where the carrier status is thought to be between 5 and 7% (Ishaq *et al.* 2012). Iran, South China, the Mediterranean, Arab nations, South Asia, and Africa are among regions where beta-thalassemia major is prevalent. Cyprus has the highest documented carrier frequency which is (14%), Sardinia (10.3%) and South Asia

(1-9%). In Pakistan, the prevalence of the beta-thalassemia gene ranges from 5 to 8%, and it affects all ethnic groups, It is found that 9 million beta-thalassemia carriers are present in Pakistan which cause more than 5000 new cases of transfusion-dependent thalassemia (TDT) to be born each year. At the moment, Pakistan is estimated to have 100,000 cases of thalassemia which is 5% of the total globe. (Maheen *et al.* 2015, Ghafoor *et al.* 2016). These numbers are increasing due to insufficient awareness and lack educational programs and most of mothers don't known about theirs carrier status which give birth to thalassemia major child (Ghafoor *et al.* 2016). Cousin weddings are most prominent in Pakistan due to the country's cultural and religious environment. The majority of people are unaware of premarital screening and counselling for those with illness in their families. Prenatal diagnosis has also been available in Pakistan for some years, but regrettably few couples are aware of it, and the expense of the test itself has further discouraged general community use. However, it is still true that even after doing prenatal testing for thalassemia, the couple is still not given the option of an abortion due to ethical, religious, and cultural considerations. The primary preventative techniques include informing the public and professionals appropriately, screening and counselling at-risk families, and screening the general population prior to marriage (Ishaq *et al.* 2012) (Taher *et al.* 2021). Iron store in body in the form of ferritin and small amount of ferritin is release into the plasma in the absence of inflammation, the amount of total body iron stored is associated with the quantity of this plasma (or serum) ferritin by age and sex, the normal ferritin concentration varies (Mishra *et al.* 2013). Thalassemia patients who require 2–5 weekly RBC transfusions end up having an excess of iron in their bodies. In the body, which lacks any mechanisms for excreting iron, each unit-packed RBC delivers 200 mg of iron. (Suriapperuma *et al.* 2018). After the reticuloendothelial system phagocytose transfused red blood cells and attaches to circulating plasma transferrin (two iron molecules), labile cellular iron (LCI) is released. Non-transferrin-bound iron (NTBI) appears in plasma and assembles in several types of cells when transferrin's ability to bind iron is high (transferrin saturation 60–80%): cells from the pancreas, heart, pituitary, and liver (Suriapperuma *et al.* 2018, Pinto *et al.* 2020). The free iron deposit in vital organ like liver, heart and endocrine glands due to which their normal functioning disturbs which cause Cardiac siderosis, cardiac failure, abnormal heart rate, myocarditis, pericarditis and heart attack which is the leading cause of death in thalassemia major patients, which account for 71% of death (Prabhu *et al.* 2009). The inability of human beings to get rid of excess iron and expose patients of transfusion dependent thalassemia to toxic effect of iron, consequently patients do not die due to anemia but die in early life due iron-induce cardiomyopathy. (Pinto and Forni 2020) The "gold standard" for determining the full body's iron reserves has been liver biopsy with biochemical determination of the liver's iron content. An increased risk of iron-induced heart disease has been linked to liver iron concentrations of 15 mg/g dry weight or higher (Prabhu *et al.* 2009). The goal of treating iron overload is to achieve a neutral or negative iron balance by bringing the plasma and cytosolic concentration of reactive low-molecular-weight "labile" iron pools—which are continually generated—to zero and preventing tissue damage from iron (Pinto and Forni 2020). (Prabhu *et al.* 2009). The most commonly used iron chelator, desferrioxamine, remove about 30-70 mg of iron per day. Chelators tightly bind to iron, preventing the ion from catalyzing redox processes. There are six

electrochemical coordination sites for iron ions. Therefore, chelators that bind to all six sites are referred to as "hexadentate," and deferoxamine is an example of one. They entirely inactivate the "free" iron. The term "bidentate" refers to some chelators that bind to single molecules on iron that have only two coordination sites; e g deferiprone (Prabhu *et al.* 2009).

(Singh *et al.*) Stem cell transplant is the only treatment option that would completely cure thalassemia, although this service is only offered in a few hospitals in Pakistan. But unfortunately, a huge percentage of patients cannot afford the usual cost of a stem cell transplant, which ranges from $25,000 to $40,000(Ali *et al.* 2015).

The introduction of a carrier screening program, genetic counselling, prenatal diagnosis, and selective termination of affected fetuses is the greatest strategy to lessen the burden on society and the occurrence of disease. Due to insufficient knowledge and lack of awareness regarding the inheritance pattern which increased the number of patients (Barua *et al.* 2021). Superstition about heredity and certain socio-cultural reluctance to screening also play a significant part. However, for a variety of ethical and cultural reasons, premarital testing is not permitted in several nations (Barua *et al.* 2021). Education of the general public is the greatest strategy to halt the disease and reduce its morbidity and mortality.

Thalassemia management is a significant burden on both the healthcare system and the families of those affected. Furthermore, patients and their families are significantly affected psychosocially and emotionally by the societal stigma associated with having thalassemia. (Wong *et al.* 2011) Being a thalassemia carrier in Asia resulted in stigmatization, marital conflict, and societal exclusion. Therefore, preventing childbirth is more crucial than ever in order to lower the disease's prevalence. Evidence suggests that the burden of disease has been significantly reduced as a result of prenatal diagnosis. However, a lack of information and understanding of the condition, its effects, psychosocial and cultural issues may act as a barrier to testing for thalassemia as well as to prevention, disclosure, and prevention. For instance, it is reportedly common for Muslim couples to object to prenatal diagnosis on religious grounds. (Wong *et al.* 2011).

The significance of this study is to determine Awareness and practices regarding thalassemia among parents of transfusion dependent beta thalassemic children register with Hamza foundation Peshawar. Premarital screening and prenatal diagnosis was known to 97 (84.3%) and 88 (76.5%) parents respectively. Ninety-nine parents (86.1%) knew about the termination of pregnancy on positive prenatal test but only 69 considered it acceptable spiritually (60%) (Ishaq *et al.* 2012). This study included only the transfusion dependent beta thalassemia patients registered with Hamza Foundation Peshawar having regular visits to hematology unit either for clinical checkup along with laboratory follow-up or regularly scheduled blood transfusion will be included in the study. The excluded transfusion dependent beta thalassemia patients having co-morbidities i.e. Sickle beta + thalassemia or thalassemia patients with any associated chronic disease not related to thalassemia or its complications will be excluded.

Materials and Methods

The Descriptive Cross-sectional study was conducted at Hamza Foundation Welfare Thalassemia, Hemophilia Hospital in which Non Probability - Convenient sampling of total 150 sample was collected.

Statistical Analysis

Statistical Package for Social Sciences (SPSS) version 22 was used for the analysis of the data.

Data Collection Procedure

This study will be conducted after approval from ethical review board of institute. The data obtained will be kept anonymous and ensure its confidentiality by principal investigator. Consent form will be taken from all the participant before enrolling them. The data collection instrument will be questionnaire adopted form a study conducted by Ahmed et al 2020 (Ahmed *et al.* 2020) having variable of interest pertaining to awareness and practices of parents of transfusion dependent b- thalassemia affected patients

Results

Table 1 Gender, Education, Resident and Age of the participants

S/No	Variable		Frequency	Percentage
1.	Gender	Male	74	49.3
		Female	76	50.7
2.	Education	Primary	56	37.3
		Secondary	44	29.3
		Higher Secondary	34	22.7
		Graduation	16	10.7
3	Resident	Peshawar	65	43.3
		Charsadda	33	22.0
		Khyber Agency	17	11.3
		Kohat	8	5.3
		Mohmand Agency	15	10.0
		Khrram Agency	5	3.3
		Malakand	7	4.7
4	Age	20 -30	33	22
		31-40	58	38.6
		41-50	45	30
		51-60	13	8.6

In the above table data were collected from population of 150 in which 49.3% were male and 50.7% were female. 37% of population are educated up to primary, 29 % secondary, 22.7% higher and only 10.7% are gradated. 43.3% population are from Peshawar, charsdda (22%), Khyber agency (11.3%), Kohat (5.3%), Mohmand agency (10%), Khurram agency (3.3%) and from Malakand are 4.7%. data were collected from different age groups of parents range from 20 to 60 in

which 22% parents were from 20 to 30 group age, 38.6% from 31 to 40, 30% from 41 to 50 and 8.6% from 51 to 60 group of age.

Table 2: Awareness about Thalassemia

S/N	Variable		Frequency	Percentage
1.	Did you have knowledge about thalassemia before Your first child was affected?	Yes	58	38.7
		No	92	61.3
2.	What is your perception about thalassemia?	Genetic	34	22.7
		God will	116	77.3
3.	Do you know cousin marriage play a role in transmission to upcoming generation?	Yes	71	47.3
		No	79	52.7
4.	Do you know about the treatment of thalassemia if yes which one is best?	Blood transfusion	87	58
		Bone marrow transplant	40	26.7
		Don't know	23	15.3
5.	Do you think it is necessary for both parents to get screened before they get married?	Yes	91	60.7
		No	58	38.7
6.	Do you know how the thalassemia can be prevented?	Genetic counseling	24	16
		pre-natal diagnosis	35	23.3
		Pre-marital screening	83	55.3
		Don't know	8	5.3
7.	Do you have knowledge about premarital screening?	Yes	21	14
		No	129	86
8.	Do you think this disease is prevailing in Pakistan?	Yes	77	51.3
		No	73	48.7
9.	Do you think there should be arranging more awareness program regarding thalassemia?	Yes	145	97.3
		No	4	2.7
10.	Do you have knowledge about iron overload and its consequence?	Yes	103	68.7
		No	46	30.7
11.	Till now, what has been the effect of your child's disease on you	Anxiety	81	54
		Sympathy	51	34
		Others	18	12
12.	Do you have thalassemia gene?	Yes	136	90.7
		No	14	9.3
13.	Do you know that you are responsible for transfer of thalassemia to your child?	Yes	128	85.3
		No	22	14.7
14.	Do you know thalassemia can be detected during pregnancy?	Yes	84	56
		No	66	44
15.	Is there any permanent treatment of thalassemia?	Yes	19	12.7
		No	131	87.3
16.	Can thalassemia be spread by food, medicine or infection?	Yes	17	11.3
		No	133	88.7
17.	Do you think regular blood transfusion is the only treatment?	Yes	91	60.7
		No	59	39.3
18.	Is iron containing food healthy for thalassemic child?	Yes	55	36.7
		no	95	63.3

In the above table data were conducted from population of 150 though questionare about awareness of thalassemia. In which 58(38.7%) had knowledge about thalassemia before their first child were affected and 92(61.3%) didn't known about thalassemia.34 (22.7%) individual known that thalassemia is genetic disorder but large portion of population 116(77.3%) consider it as God will. Out 150 71(47.3%) believe that thalassemia spread due to cousin marriages and 79(52.7%) don't think so. 87(58%) consider blood transfusion is the treatment of choice and 40(26.7%) think that bone marrow transplant is the treatment of choice but 23(15.3%) didn't known about treatment of thalassemia.91(60.7%) think that it is necessary for a couple to get screened before they get married and 58(38.7%) don't think so that it is necessary to be screened before marrage.24(16%) think that genetic counseling will help In prevention of thalassemia while 35(23.3%) believe that pre-natal diagnosis can prevent thalassemia and 83(55.3%) consider pre-marital screening is best for thalassemia prevention but 8(5.3%) didn't known about thalassemia prevention.21(14%) individuals had knowledge about pre-marital screening on other hand 129(86%) didn't known about pre-marital screening. 77(51.3%) people think that thalassemia is rising in Pakistan while 73(48.7%) think opposite. Almost all the population 145(97.3%) think that there should be programs regarding awareness of thalassemia while little part believe that no need of programs regarding thalassemia. Some individual 103(68.7%) were aware of iron overload and its consequence while 46(30.7%) have no knowledge about it. 81(54%) were in anxiety due to their thalassemic child while 51(34%) had sympathy with their thalassemic child and 18(12%) had other impact. About 136(90.7%) believe they had gene for thalassemia while 14(9.3%) didn't think so. Out of 150 128(85.3%) were aware of that they can transfer thalassemia to their child while 22(14.7%) were not aware. 84(56%) known that thalassemia can be detected during pregnancy while 66(44%) don't known that thalassemia is detectable during pregnancy.19(12%) individuals think that is a permanent treatment of thalassemia while large proportion of population 131(87%) no think that there is permanent treatment for thalassemia.17 (11.3%) individuals think that thalassemia can be transfer by food, medicine and infection while 133(88.7%) don't consider that can be transfer by food, medicine and infection.91(60.7%) believe that regular blood transfusion is only treatment for thalassemia while 59 (39.3%) don't think same.55 (36.7%) think that iron containing food are healthy our child while 95(63.3%) don't that iron healthy for their thalassemia child.

Table 3: Practices Regarding Thalassemia

S/No	Variable		Frequency	Percentage
1.	Have you both partners undergo screening before getting married?	Yes	6	4
		No	144	96
2.	If answer of question 1 is no then what was the reason that you didn't get screened?	Lack of knowledge	146	97.3
		Religious beliefs	4	2.7
3.	Are your other children screened?	Yes	57	38
		No	93	62
4.	Have you motivated any one for pre-marital screening?	Yes	136	90.7
		No	14	9.3
5.	Do you wish for more children despite of already having sick ones?	Yes	114	76
		No	36	24

S/No	Variable		Frequency	Percentage
6.	Do you encourage your child to take medicine regularly?	Yes	148	98.7
		No	2	1.3
7.	Do you share food among your children?	Yes	141	94
		No	7	4.7
8.	Have you ever received genetic counseling?	Yes	20	13.3
		No	67	44.7
		Don't know	63	42
9.	Do you have practices of iron chelation therapy for your children?	Yes	32	21.3
		No	79	52.7
		Don't know	39	26
10.	Have the female partner got her chorionic villus sampling (CVS) test done during her pregnancy?	Yes	84	56
		No	66	44
11.	If CVS was positive, did you option for abortion?	Yes	36	24
		No	47	31.3

Data were collected from population size of 150 about practice regarding thalassemia which presented in this table. 6(4%) individuals were screened before marriage while 144(96%) were not screened before marriage and the reason for not getting screened were lack of knowledge (97.3%) and religious beliefs (2.7%).57(38%) have screened their other children while 93(62%) didn't find it important to screened their other children.136 (90.7%) individuals have motivated other for pre-marital screening while 14(9.3%) have not motivated any one. Out of 150 114(76%) couple were wishing for another child while already have sick one and 36(24%) didn't wish for another child because of already thalassemic child. 148(98.7%) were encouraging their child to take medicine regularly while 2(1.3%) didn't encourage their child to take medicine and 141(94%) parents were sharing food among their children while 7(4.7%) didn't share food among their children. 20(13.3%) patients have received genetic counseling while 67(44.7%) have not received genetic counseling and 63(42%) patients had no knowledge about genetic counseling. 32(21.3%) parents were giving iron chelation therapy while 79(52.7%) parents were not giving iron chelation therapy to their children and 39(26%) parents didn't know about iron chelation therapy. 84(54%) of their female partner have done CVS(chorionic villus sampling) during their pregnancy while 66(44%) female has not done CVS. Out of 84 which has done CVS 36(24%) female had abortion while 47(31.3%) had no abortion and birth to thalassemic child.

Table 4: Demographic Awareness Regarding Thalassemia

S/No	Demographic		Awareness Regarding Thalassemia			
			Good Awareness	Poor Awareness	Total	P- value
1	Gender	Male	52	21	73	0.203
		Female	46	29	75	
2	Education	Primary	30	25	55	0.030
		Matric	28	16	44	
		Higher Secondary	27	7	34	
		Graduation	13	2	15	
3		Peshawar	44	20	64	
		Charsadda	23	10	33	

S/No	Demographic		Awareness Regarding Thalassemia			
			Good Awareness	Poor Awareness	Total	P- value
	Residence	Khyber Agency	9	7	16	0.956
		Kohat	5	3	8	
		Mohmand Agency	9	6	15	
		Khuram Agency	3	2	5	
		Malakand	5	2	7	
4	Age groups	20-30	18	15	33	0.138
		31-40	39	19	58	
		41-50	30	15	45	
		51-60	11	1	12	

Data were collected from 150 parents of thalassemia patients which is categorized on basis of gender in which male were slightly more aware than female. 52 male had good awareness regarding thalassemia while 21 were poorly aware and 46 female were aware while 29 has poor awareness. The degree of awareness among student of primary education in which 30 had good awareness regarding thalassemia while 25 were poorly aware and 28 matric students has good awareness while 16 do not has good awareness. 34 higher secondary students were involve in which 27 had pretty good awareness about thalassemia while 7 were not aware.13 graduation students had good awareness while 2 had poor awareness. Awareness regarding thalassemia on basis of residence 64 people were added from Peshawar in 44 had good awareness about thalassemia while 20 had poor awareness. 23 individuals from charsadda had good awareness while had poor awareness regarding thalassemia. 9 couple from Khyber Agency had good awareness and 7 had poor awareness.5 from Kohat had good awareness while 3 had poor awareness about thalassemia. 9 from Mohmand Agency had good awareness while 6 individuals had poor awareness. 3 individuals from Khurram Agency were fully aware while 2 were not aware of thalassemia. 5 couple from Malakand had good awareness while 2 had poor awareness. Awareness among individuals of different age groups fron 20-30 18 individuals had good awareness while 15 had poor awareness. 39 individuals from 31-40 group of age were fully aware about thalassemia while 19 were aware pretty much. 30 from 41-50 group of age had good awareness while 15 had poor awareness regarding thalassemia.11 individuals from 51-60 age group had good awareness while only 1 had poor awareness about thalassemia. Chi square test was applied to data in which association between education and awareness regarding thalassemia were significant (Education vs awareness regarding thalassemia p value = 0.030) while gender, age and residency were not significantly in association with awareness regarding thalassemia there value was higher than 0.05**.**

Table 5: Demographic Practices Regarding Thalassemia

S/No	Demographic		Practices Regarding Thalassemia			
			Good Practices	Poor Practices	Total	P value
1	Gender	Male	59	15	74	0.00
		Female	40	36	76	
2	Education	Primary	33	23	56	0.255
		Matric	29	15	44	
		Higher Secondary	27	7	34	
		Graduation	10	6	16	
3	Residence	Peshawar	42	23	65	0.432
		Charsadda	25	8	33	
		Khyber Agency	10	7	17	
		Kohat	6	2	8	
		Mohmand Agency	7	8	15	
		Khuram Agency	3	2	5	
		Malakand	6	1	7	
4	Age groups	20-30	23	10	33	0.290
		31-40	43	16	59	
		41-50	25	20	45	
		51-60	8	5	13	

Data were collected from 150 parents of thalassemic child about practice regarding thalassemia in which male had little more practice than female 59 male had good practice on other hand 15 had poor practice while 40 females had good practice and 36 poor practices. Practice regarding thalassemia in association with education in which 33 students from primary education had good practice while 23 had poor practice regarding thalassemia. 29 students from matric had good practice while 15 had poor practice. 27 students of higher secondary had good practice while 7 had poor practice. 10 graduate students had good practice while 6 had poor. Practice regarding thalassemia in association with residency in which 42 parents had good practice while 23 had poor practice. 25 couple from Charsadda had good practice while 8 had poor. 17 parents were involved from Khyber Agency in which 10 had practice while 7 had poor practice. 6 couple from Kohat had practice while 2 had poor practice. 7 from Mohmand Agency had well while 8 had poor practice. 3 parents from Khurram Agency had good practice while 2 had poor practice. 6 couple from Malakand had good practice while 1 had poor practice. Association of practice regarding thalassemia in different groups of age in which 23 from age group of 20-30 had good practice while 10 had poor practice. 43 parents from 31-40 of age had good practice while 16 had poor practice. 25 couple from 41-50 of age had good practice while 20 had poor practice. 8 parents of age 51-60 had good practice while 5 had poor practice regarding thalassemia. Chi square test was applied to data in which association between gender and practice regarding thalassemia were significant (Gender vs practice regarding thalassemia p value = 0.00) while education, age and residency were not significant because there value were high than 0.05

Discussion

Thalassemia is an genetic (autosomal recessive) disorder of haemoglobin production, in which there is incomplete or complete failure to synthesize a specific type of globin chain, alpha chain in alpha-thalassemia and beta chain in beta-thalassemia. Our study is about awareness and practices regarding beta thalassemia among parents transfusion dependent beta thalassemia children. This study is carried out in hamza foundation welfare thalassemia hospital Peshawar, Pakistan.

In this study data was collected from population of 150 in which 92(61.3%) had no knowledge about thalassemia and 34(22.7%) individual know that thalassemia is genetic disorder where 71(47.3%) parents believe that thalassemia occurred due cousin marriage. In our study knowledge regarding thalassemia is poor as compared to Ghafoor et al (60%), farhad et al(82%) and faouzia et al(81.7%).(1,8,2) .According to kalra 100% parents knew about blood transfusion being primary management of thalassemia, 100 % knew about bone marrow transplantation being best choice for thalassemia treatment which is much better than present study which is 87(58%) consider blood transfusion is primary management and only 26.7% think that bone marrow is best choice of treatment(4). It was resulted in the study of singh et al that 65.7% parents think that premarital screening is a choice of prevention for thalassemia while 51.4% think prenatal screening is best option. In current study 60% individual think that premarital screening can prevent thalassemia and 23.3% goes for prenatal screening (17).

Ahmed et al mention in his study 64.7% parents had knowledge about iron overload and its consequence while 41% had no knowledge. 51.2% parents were suffering from anxiety due thalassemic child while 23.4% had sympathy with their child. In current 54% parents were suffering anxiety while 34% were sympathy. In our study most of the population are unaware about thalassemia and didn't their genetic nature due to lack of education and awareness about the disease and its prevention.

As regard to practice it was observed from this study that only 4% individuals were screened before marriage while 96% were not screened before marriage and the reason for not getting screened were lack of knowledge (97.3%) and religious beliefs (2.7%). While ahmed et al,(39). Study shows that 64.2 % of parents had not screened before marriage due lack of knowledge (33.3%) and religious beliefs (17.4%). Although, Ahmed et al noted that 47.8 % parents had screened their other children, and 87.6 % couple had motivated other to get premarital screening done. Current study revealed 38% parents had screened their other children while 90.7% individuals had motivated other for pre-marital screening. In this study most of the population had not undergone premarital screening and didn't screened their healthy children because lack of knowledge, religious beliefs and didn't know the carriers status of their healthy children. Surprisingly 76% population were wishing for another child who already had a thalassemic child because of religious beliefs and they think its God well. And 21.3% parents were aware and giving the treatment of iron chelation therapy for prevention of iron overload and 26% parents didn't know about iron chelation therapy reveal that

80.0% of the parents were also well aware of the iron chelation therapy as the prevention and treatment of iron-overload in the thalassemia patients.

Demographic analysis of this study showed that male were little more aware and had better practices about thalassemia than female. Awareness and practices regarding thalassemia in this study were categorized on the basis of education into primary, matric, higher secondary and graduation in which parents who were graduated had good awareness and those parents who were educated till higher secondary had more practices about thalassemia as compared to other. Awareness and practices of current is similar to Basu et al(7) and wong et al(11) study. Currents study revealed that Parents of different age range from 20 to 60 among these 31 to 40 age of parents had good practices regarding thalassemia and those parents who had good knowledge about thalassemia is from 51 to 60 age of parents while in basu et al resulted in his study parents of age less 45 had good knowledge regarding thalassemia

Conclusions & Recommendation

Conclusion

The present study concluded that the awareness of parents regarding this chronic illness was inadequate and these patients will continue to suffer a slow and painful course. Male shows predominance over female regarding awareness and practices of disease therefore different educational and interventional program is required about the preventive aspects of thalassemia to reduce burden.

Recommendation

A larger scale study with extensive sample size required for drawing larger picture of disease awareness and practices follows in our community. Moreover, our community needs extensive preventive measures employing educational institutions, masjids/madarsas, print and electronic media and through seminars, symposia and workshops. Public health messages should be spread to clear the misconceptions and promote the screening of carriers and prenatal diagnosis. Beside developing strategies to educate the disease population or cargiver of thalassemia parents above mentioned program eventually lead to a reduction in thalassemia births and will ultimately eradicate this fatal disease.

Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this paper.

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