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Research Article

KNOWLEDGE, ATTITUDE AND PRACTICES (KAP) OF THE FAMILIES OF B- THALASSEMIA PATIENTS IN A THALASSEMIA CENTER OF KARACHI

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ABSTRACT

Introduction: Thalassemia is an inherited disorders of hemoglobin synthesis, from mild to severe in intensity, resulting from the partial or complete failure in synthesis of one or more globin chains. Pakistan is one of the states that has a high prevalence of beta thalassemia. It is predicted that about 9000 kids with beta thalassemia are born per year.This study is premeditated to understand the knowledge, attitude and practices of parents of beta thalassemia major children.

Methods: The cross-sectional KAP study was conducted from January 2018 to September 2018. Only 201 participants were included in the study who complete the given form. Additionally, the questionnaire was also translated in Urdu for the ease of parents. A pilot study was conducted to rule out any uncertainty.

Results : Our study comprise of 201 thalassemia patients, out of which 103(51.2%) were male and 98(48.8%) were female. Upon evaluating the knowledge half [109(54.2%)] of the parents had no earlier knowledge about thalassemia. A Significant variation was noted when about their perception of thalassemia (P=0.001). Another, noteworthy correlation were appreciated when parents were asked about the screening before marriage (P=0.001). When compared the attitude of parents towards intermarriages of thalassemia carriers the outcome was significant (P=0.006).

Discussion: The consequences of our study shows an enthralling dichotomy, a larger percentage (64.2%) were from rural areas as expected, 77.6% reported consanguineous marriages a major risk factor for the disease. In our country the lack of proper resources to facilitate patients of thalassemia making prevention programs the leading choice [9]. Moreover, 23.4 % of mothers had received PD, only 9.95 % opted for an abortion if the fetus was positive for Thalassemia. The one exemption to the rule was the fact that an appreciable 56.7 % disclosed having received genetic counseling.

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INTRODUCTION

Thalassemia is a group of inherited disorders of hemoglobin synthesis, marked by mild to severe hypochromic microcytic anemia, resulting from the partial or complete failure in production of one or more globin chains. Four alpha genes and two beta genes are responsible for globin chain synthesis. Each gene mutation leads to a different phenotype of varying severity, with defects in beta genes producing more severe consequences commonly referred to as Cooley's anemia. Worldwide, mutations in beta genes is the most common form of hereditary hemoglobinopathy and isbecoming one of the challenging health problems due to its high prevalence. [1]

It is most commonly and particularly seen in Mediterranean region, Africa, Middle East, the Indian sub-continent, Southeast Asia, Melanesia and the Pacific Islands. The percentage in these areas has reached up to 20.0%. [1, 2, 3] Pakistan is also one of the states that has very high incidences of beta thalassemia. [4] It is estimated that about 9000 children with beta thalassemia are born every year, although no documentary registry is available in Pakistan. The estimated carrier rate is 5-7%, which accounts for 9.8 million carriers in the total population. This can be attributed to high ratio of consanguineous marriages, no concept of prenatal screening and genetic counseling, inaccessibility to antenatal screening and termination of pregnancy being considered unethical and against religious beliefs. [5]

Study performed in Lahore to assess parental knowledge of beta thalassemia, revealed that, most of the couples (81.7%) had consanguineous marriage, majority knew that thalassemia is an inherited disorder and were aware of premarital screening and prenatal diagnosis but very few had knowledge about detection of thalassemia carrier state, (86.1%) of parents knew about the termination of pregnancy on positive prenatal test

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but only 60% considered it acceptable religiously. Major source of information to the parents were doctors.[6] Research done in Karachi in 2007, showed that only 15% knew that thalassemia is an inherited disorder and family screening of the siblings was done in only 5.8% cases, while, antenatal diagnosis was reached only in 5% pregnancies. [7]

Therefore, this cross sectional study is planned to comprehend the gap of knowledge, attitude and practices of parents of beta thalassemia major children visiting in Patients Welfare Association's thalassemia daycare center, which is one of the biggest thalassemia centers in Karachi.

METHODOLOGY

The cross-sectional KAP study was conducted with proportionate stratified random sampling technique from January 2018 to September 2018. The study was conducted at the Thalassemia center of Patient Welfare Association. All parents that showed up to these centers were interrogated by using a questionnaire, after unwritten informed consent. Patients with other blood disorder like alpha thalassemia, thalassemia intermedia, hemophilia, thrombocytopenia, aplastic anemia, Fanconi anemia, hemolytic anemia, iron-deficiency anemia, lymphoblastic leukemia, and sickle cell anemia etc. were excluded. The study comprised of a total of 217 participants. Out of these 11 participants denied consent. 5 more left without completing the interview. Consequently, by using the openepi.com, the cooperation rate was 95.9%. Only those 201 participants were included in the studywho gave complete data. All the participant were interviewed using a standard pre-designed questionnaire. The interview was conducted by 2 trained interviewers who were fluent in Urdu (the national language) and other regularly spoken languages in adjacent areas to elude any possible miscommunication and to guarantee all eligible patients were successfully interviewed. Furthermore, the questionnaire was also translated in Urdu remembering that all the patient coming to these centers won't be comfortable with English. A pilot study was done to check for any uncertainty. The questionnaire comprises of four sections. The first section inquires about children personal information, their relation with the patient, the area they belong to, cousin marriage etc. Second section covers questions which access their knowledge concerning thalassemia. The third section deals with their practice towards thalassemia testing/counseling. The final section states the opinion/ attitude of parents regarding pre-marriage/ pre-natal thalassemia testing. A two-point scale (Yes/No) was used to measure these questions.

RESULT

A total of 201 thalassemia patients were included in our study, out of which 103(51.2%) were male and 98(48.8%) were female. 131(65.2%) were from rural areas, while, remaining 70(34.8%) were from urban areas. Upon inquiring, 156(77.6%) children's parents were cousins, while, 45(22.4%) were not. At the time of survey, 88(43.8%) children were accompanied by mother, while, remaining 113(56.2%) were accompanied by father.

Upon assessing the knowledge of parents about thalassemia, we came up with following results:About half [109(54.2%)] of the parents stated that they had no knowledge about thalassemia before their child was affected, however, almost half [125(55.7%)] of them mentioned that they knowcousin marriages play a key role in the spread of the disease. Also that almost half of parents [106 (53%)] had opinion that this disease is prevalent in Pakistan and likewise, a huge majority, 194 (97 %) of parents suggested that there should be more awareness programs regarding thalassemia in Pakistan. Majority [125(62%)] had a relative suffering from thalassemia and majority [139(69.1%)] of them agreed that it's necessary for both parents to get screened before marriage. Though a significant majority [133(66%)] had knowledge about premarital screening, very less [74(36%)] number of parents knew about prenatal diagnosis of thalassemia. Surprisingly, a vast majority [136(67.6%)] had knowledge about iron overload and its consequences.

Furthermore, the parents gave almost equal amount of data for their source of knowledge about thalassemia.Sources being awareness session, relatives and media.The most popular perception about thalassemia was that it's a genetic disorder [96 (47.8%)] and a great majority marked blood transfusion as the best treatment option [91(45.3%)]. On the contrary, greater number of parents didn't knew of how can thalassemia be prevented [104(51.7%)].

Upon assessing the practices of parents, it was found out that majority of the population tested [129(64.2%)] didn't go for screening. The frequently marked reason of not getting screened was found to be poverty [56(27.9%)], while [35(17.4%)] people marked religious beliefs and [39 (19.4%)] people marked family/elder influence to be the reason. Moreover, an overwhelming majority of parents 154 (76.6%) did not go for CVS (chorionic villous sampling) and likewise, a vast majority 154 (76.6%) also didn't know whether to opt for abortion if CVS test came positive. Surprisingly, almost half of the parents got their other children screened. It was very good to see that a huge majority 176(87.6%) of parents had motivated others for premarital screening. Many people, 116(57.7%) still wished for more children despite of having a sick one. 169(84%) parents were not reluctant of telling their child's disease to their relatives and had told them. A greater proportion of parents that were:129 (64.2%) who encouraged their child to take medicine regularly, 185(92%) who shared food common among their children and 114(56.7%) who had received genetic counseling.

When the attitude of parents was assessed, a bulk of them marked disagrees or strongly disagrees option for intermarriages of thalassemia carriers. However, majority agreed on carrier couple having a child option. Greater number of parents strongly agreed for pre-marital screening option and also agreed for the need of legislation for pre-marital screening. Termination of pregnancy if fetus is thalassemia positive was strongly agreed upon.Lastly, our data shows that the child's condition majorly caused anxiety in 103(51.3%) parents and secondly, some also developed sympathy [47(23.3%)] for their child.

We compared parents coming from rural areas with those from urban areas. Chi-square test was applied and p-value<0.05, suggested that the result is significant. Significant difference was seen when parents were asked about their perception of thalassemia (P=0.001), whether they knew about the treatment of thalassemia or not (P=0.001) and the effect their child's on them (P=0.032). For practice related questions significant differences were seen when parents were asked whether both partners had undergone screening before marriage (P=0.001), did the female partner had her CVS test done during pregnancy

(P=0.01), if CVS came out positive, did they opt for abortion (P=0.001), are your other children screened (P=0.02) and have you motivated others for pre-marital screening (P=0.02).In attitude section, only when asked about the attitude of parents towards intermarriages of thalassemia carriers the results came significant (P=0.006).

Table 1 Demographic Data

Gender	Frequency	Percentage
Male	103	51.2%
Female	98	48.8%
Residence	**Frequency**	**Percentage**
Rural areas	129	64.2%
Urban areas	72	35.8%
Cousin marriage	**Frequency**	**Percentage**
Yes	156	77.6%
No	45	22.4%
Children accompain by	**Frequency**	**Percentage**
Mother	88	43.8%
Father	113	56.2%

Table 2 Knowledge regarding thalassemia'

		Rural area N= 129	Urban area N= 72	P-value
Did you have knowledge about thalassemia before your first child was affected	Yes	55 (61.1%)	37 (33.3%)	0.414
	No	74 (66.7%)	35 (38.9%)	0.001
If yes in question 1, from where did you get to know about thalassemia?				
	Awarness session	35 (81.3%)	25 (58.1%)	
	Relatives	51 (98.1%)	1 (1.9%)	
	Media	34 (54.0%)	29 (46.0%)	
	Others	9 (34.6%)	17 (65.4%)	
What is your perception about thalassemia				0.001
	A genetic disorder	73 (66.4%)	23(56%)	
	Don't know	21 (77%)	6 (22%)	
	God will	28 (21.7%)	33 (45.8%)	
	Infectious disease	11 (64.7%)	6 (35.3%)	
Do you know cousin marriage play a role in transmission to upcoming generation	Yes	79 (63.2%)	46 (36.8%)	0.840
	No	22 (68.8%)	10 (31.3%)	
	Don't know	28 (63.6%)	16 (36.4%)	
Do you know about the treatment of thalassemia if yes which one is best	Folic acid supplement	32 (74.4%)	11 (25.6%)	0.001
	Blood transfusion	66 (72.5%)	25 (27.5%)	
	Bone marrow transplant	31 (47.7%)	34 (52.3%)	
Do you think it is necessary for both parents to get screened before they get married	Yes	87 (62.2%)	52 (37.4%)	0.480
	No	52 (37.5%)	20 (32.3%)	
	Don't know	73 (70.2%)	31 (29.8%)	
Do you know how the thalassemia can be prevented				0.068
	Genetic counseling	23 (76.6%)	7 (23.3%)	
	Pre-marital screening	11(64.7%)	7 (41%)	
	Pre-natal diagnosis	8 (66.6%)	4(33.3%)	
Do you have any relative suffering from thalassemia	Yes	85 (68.0%)	40 (32%)	0.147
	No	44 (57.9%)	32 (42.1%)	
Do you think this disease is prevailing in Pakistan	Yes	71 (67%)	35 (33%)	0.38
	No	58 (61.1%)	37 (38.9%)	
Do you think there should be more awareness program regarding thalassemia	Yes	125 (64.4%)	69 (35.6%)	0.69
	No	4 (57.1%)	3 (42.9%)	
Do you have knowledge about iron overload and its consequence	Yes	88 (64.7%)	48 (35.3%)	0..82
	No	41 (63.1%)	24 (36.9%)	
Till now, what has been the effect of your child's disease on you				0.032
	Anxiety	53 (52.3%)	50 (47.7%)	
	Sympathy	28 (59.7%)	19(40.3%)	
	Aggression	23(69.7%)	10 (30.3%)	
	Gratitude	10 (55.5%)	8 (44.5%)	
Do you have knowledge about premarital screening	Yes	87 (65.4%)	46 (34.6%)	0.61
	No	42 (61.8%)	26 (38.2%)	
Do you have knowledge about prenatal diagnosis of thalassemia	Yes	44 (59.5%)	30 (40.5%)	0.28
	No	85 (66.9%)	42 (33.1%)	

Table 3 Practice regarding Thalassemia

		Rural area	Urban area	P-value
Have you both partners undergo screening before getting married	Yes	29 (40.3%)	43 (59.7%)	0.001
	No	100 (77.5%)	29 (22.55)	
If answer of question 1 is yes then what was the reason that you didn't get screened	Lack of knowledge	48 (71.6%)	19 (28.4%)	0.014
	Poverty	39 (69.6%)	17 (30.4%)	
	Religious beliefs	16 (45.7%)	19 (54.3%)	
	Family/ elder influence	24 (61.5%)	15 (38.5%)	
	Lack of diagnostic features	2 (50%)	2 (50%)	
Have the female partner got her CVS test done during her pregnancy	Yes	19 (40.4%)	28 (59.6%)	0.01
	No	110 (71.4%)	44 (28.6%)	
If CVS was positive, did you opt for abortion	Yes	8 (40.0%)	12 (60.0%)	0.001
	No	11 (40.7%)	16 (59.3%)	
	Don't know	110 (71.4%)	44 (28.6%)	
Are your other children screened	Yes	51 (53.1%)	45 (46.9%)	0.025
	No	78 (74.3%)	27 (25.7%)	
Have you motivated any one for pre-marital screening	Yes	120 (68.2%)	56 (31.8%)	0.028
	No	9 (36%)	16 (64%)	
Do you wish for more children despite of already having sick ones	Yes	78 (67.2%)	38 (32.8%)	0.290
	No	51 (60%)	34 (40%)	
Is your child's disease know to your relatives	Yes	121 (64%)	68 (36%)	0.857
	No	8 (66.7%)	4 (33.3%)	

Do you encourage your child to take medicine regularly	Yes	100 (77.5%)	29 (29%)	0.570
	No	55 (76.3%)	17 (23.6%)	
Do you share food among your children	Yes	116 (62.7%)	69 (37.3%)	0.136
	No	13 (81.3%)	3 (18.8%)	
Have you ever received genetic counseling	Yes	69 (60.5%)	45 (39.5%)	0.214
	No	60 (69.0%)	27 (31.7%)	

Table 4 Attitude regarding Thalassemia

		rural area	urban area	P-value
Intermarriages of thalassemia carrier	Strongly agree	6 (54.4%)	4 (36.3%)	0.006
	Agree	15 (71.4%)	6 (28.5%)	
	Disagree	40 (63.4%)	23 (36.5%)	
	Strongly disagree	5 (6.5%)	72 (93.2%)	
	Uncertain	19 (63.3%)	11 (36.5%)	
Carrier couple having children	Strongly agree	15 (26.8%)	41 (73.2%)	0.495
	Agree	71 (92.2%)	6 (7.8%)	
	Disagree	10 (52.6%)	9 (47.4%)	
	Strongly disagree	3(33.3%)	6 (66.7%)	
	Uncertain	30 (75%)	10 (25%)	
Pre-marital screening	Strongly agree	61 (58.7%)	43 (41.3%)	0.30
	Agree	29 (64.4%)	16 (35.6%)	
	Disagree	21 (80.8%)	5 (19.2%)	
	Strongly disagree	3 (75%)	1 (25%)	
	Uncertain	15 (68.7%)	7 (31.8%)	
Termination of pregnancy if fetus is thalassemia positive	Strongly agree	51 (63%)	30 (37%)	0.900
	Agree	42 (61.8%)	26 (38.2%)	
	Disagree	6 (75%)	2 (25%)	
	Strongly disagree	10 (71.4%)	4 (28.6%)	
	Uncertain	20 (66.7%)	10 (33.3%)	
Need of legislation PMS	Strongly agree	34 (63.3%)	20 (37%)	0.714
	Agree	68 (63.2%)	40 (37%)	
	Disagree	10 (58.8%)	7 (41.2%)	
	Strongly disagree	5 (71.4%)	2 (28.6%)	
	Uncertain	12 (80%)	3 (20%)	

DISCUSSION

The results of this study showcase an intriguing dichotomy: though the populace demonstrated an above average, although still superficial, comprehension of Thalassemia, those that put this knowledge into practice were still in the minority. Of the participants, a larger portion (64.2%) were from rural areas, and only 35.8% from urban areas; as expected, [8] 77.6% reported as being a part of a consanguineous marriage, which is a major risk factor for the disease.

The superficial nature of their understanding is reflected in the fact that a large part of partaking parents (45.8%) had been aware of this condition even before being presented with their first diagnosis, but of them a large portion (30.3%) attributed its cause to God's will. Although it is worth appreciating that the base level of awareness demonstrated here is higher than that seen in other parts of Pakistan [8], thereby showing the success of awareness sessions and campaigns, it is to be noted that the most popular sources of knowledge regarding Thalassemia were Awareness Sessions (29.9%), Relatives (25.9%) and Media (31.3%). This may account for the lapse in understanding regarding the causes. Worthy of notice is that, 96.5% of participants stated that larger scale awareness programs were needed throughout Pakistan.

In a country like Pakistan, which lacks the proper resources to facilitate a thorough management of this multidisciplinary affliction, conservative treatment and prevention programs become the leading choice [9]. Therefore, the fact that the majority (62.2%) of parents had known that cousin marriages increased the probability of manifesting Thalassemia can be seen in a positive light, especially when less than a decade previously, 87.5% had shown alack of this exact knowledge [10]. Similarly, majority 51.7 % did not outright know how Thalassemia could be prevented. In concurrence with previous surveys, [9] parents with knowledge about Premarital screening (PMS) were in the majority (66.2%), although those aware of Prenatal diagnosis were in a little minority (36.8%). An amenable mentality was displayed towards both PMS and termination of an affected fetus: with numerous people (51.7%) and (40.3%) being strongly agreed to both. Parallel to this, a large segment (53.7% agreeing and 31.8% strongly agreeing) was in accord with the use of legislation to boost the use of PMS.

As is the underlying trend, even with these encouraging figures, the actual implementation of these beliefs was somewhat lacking. 64.2 % of parents had not undergone PMS, stating a previous lack of knowledge (33.3%), poverty (27.9%), religious beliefs (17.4%), familial influence (19.4%) and a lack of diagnostic resources (3%), to be the main factors. Although, it is to be noted that 47.8 % had conclusively gotten their other children screened, and 87.6 % reported to motivating other to get PMS done. Additionally, only 23.4 % of mothers had received PD, from which only 9.95 % opted for an abortion if the fetus was positive for Thalassemia. The one exception to the rule was the fact that an appreciable 56.7 % disclosed having received genetic counseling.

The extent of morbidity and mortality of children suffering from thalassemia, can be tied to the the level of knowledge regarding available treatments that their parents possess; without a timely intervention, death becomes imminent [11]. Therefore, an optimistic picture is presented as most (45.3%) saw transfusion, followed by bone marrow transplants (32.3%), and folic acid supplements (22.4%) as possible treatments [11, 12]. Another point of concern was that of chelation therapy, as iron overload very commonly leads to a multitude of complications [13]. Once again, 67.7% reported having knowledge regarding iron overload and its consequences. This can be seen as a massive improvement over prior reports [10].

Lastly, the psychosocial impact of this disease, on the parents themselves must also be considered. An Iranian study labeled such parents as 'hidden patients' due to the immense psychological and emotional burden placed upon them [14]. In line with this, our survey revealed that they were either constantly anxious (51.2%), intensely sympathetic (23.4%), holding aggression against their fortune (16.4%) or simply grateful for their child's survival (9%). 64.2% stated that they were constantly concerned whether their child was taking their medicine on time. Surprisingly, 31.3% and 38.3 % disagreed and strongly disagreed respectively, to still allowing intermarriages between known carriers, with 27.9% and 38.3% agreeing and strongly agreeing to let carrier couples still have children. This showed how much people's perceptiveness andlevel of awareness have altered from previous times and previous researches on the topic.

Limitations

A main limitation of this study was that patients were taken only from a single Thalassemia centre whereas assessment of parents from other centers could not be obtained.

CONCLUSION

Even though parental knowledge about the thalassemia carrier, screening and prenatal diagnosis have improved over the past years, still there remains a dire need of creating awareness among general population about the preventive aspects of thalassemia in order to lessen the load of the disease in Pakistan.

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