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Assessment of disease state knowledge and awareness among the guardians of thalassemia patients attending different health facilities in Quetta, Pakistan

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Abstract
Background: Thalassemia is an autosomal recessive hereditary disease, which results in abnormal hemoglobin production. The patient is thus dependent on lifelong blood transfusions, as there is no effective therapy for it. The aim of this study was to assess the awareness about thalassemia disease among the residents of Quetta, Pakistan.
Methodology: This cross-sectional prospective study was conducted in Thalassemia Centers of Hospitals of Quetta, Pakistan from March 2016 to July 2016. Data was taken from 327 parents/guardians that were attending their patients in thalassemia centers of different hospitals, out of which 73 were discarded due to poor response; total data of 254 have been analyzed. Descriptive statistics (Frequencies, Percentages, Mean, and Standard Deviation) was used to summarize the data. Inferential statistics was applied by using Chi-square test. A p-value <0.05 was considered significant level.
Results: Results of the study showed a moderate level of awareness in-spite of having appropriate knowledge about the disease, its genetic transmission, and modes of treatment, prognosis, and complications. Still, there is a room for improvement regarding thalassemia awareness among the residents of Quetta. However, a significant influence of educational status was observed in the study results.
Conclusion: The results of the present study concluded that the people of Quetta had adequate level of awareness regarding the thalassemia disease, it's mode of transmission, diagnosis and treatment.

Keywords: Thalassemia, awareness, Pakistan

Introduction
Thalassemia is one of the commonest, genetically transmitted hemolytic anemia [1]. It is described as a defect in genes of alpha or beta globin chains leading to incomplete or no production of these chains which are part of the structure of hemoglobin in the red blood cells [2]. Thalassemia ranges from minor to major. Thalassemia minor is characterized by mild asymptomatic hemolytic anemia with no obvious clinical signs whereas thalassemia major consists of symptoms of severe anemia, which appear in the first year of life and the patient needs a lifelong blood transfusion for existence. In the center lies, thalassemia intermedia (TI), which depicts those patients who show signs too gentle to be considered thalassemia major and extremely serious, making it impossible to be called thalassemia minor [3].
The populations of Middle East, South China, India, Pakistan, Central Asia, Thailand and Mediterranean countries have highest prevalence. In Pakistan, approximately 8 million of population is suffering with thalassemia. Approximately five thousand children are born with thalassemia each year and around five out of hundred are presently suffering from it [4].
Chronic anemia prompts a condition of consistent iron absorption, leading to iron over intake. This iron overload leads to majority of its subsequent inconveniences such as cardiac, hepatic, and endocrine, etc [2, 3]. The patients with thalassemia are observed to have diminished intellectual perception, attention, memory, visual talents and managerial skills which are more commonly seen in hemosiderotic individuals [5]. The thalassemia patients depend majorly on blood transfusions as a sole treatment alternative, apart from stem-cell transplantation which is quite expensive, they feel themselves as a burden not only on their families but also on society [4].

There are no specific treatment options available for thalassemia in Pakistan and the disease is not curable completely. Bone marrow transplantation, which is an ultimate way of treating the disease, also depends upon the availability of specific donor and finally acceptance by the body of recipient. Furthermore, these treatment options are very costly and people are mostly poor. Therefore, the only option is the prevention. In addition, Pakistani people are mostly uneducated and not aware about different diseases and their ways of prevention. The level of medical and social awareness for this debilitating disease among parents of thalassemia is very low. Literature suggests that, no study has been conducted in Quetta regarding its awareness. Therefore, the present study was conducted to find out the awareness in this area. This study will highlight the need of awareness campaigns for people regarding thalassemia and its prevention. We also evaluate awareness about thalassemia among the guardians of thalassemia patients. The results of this study will help to determine the areas needing further improvement in public awareness campaigns.

Methodology

Study Design and Study population

A descriptive, non-experimental, cross sectional, questionnaire based study design was adopted to conduct this study from March 2016 to July 2016.This study design was adopted due to its low cost and less time consuming nature as the cross-sectional study is conducted only at one specific point in time. Study was conducted in Thalassemia Center in the hospitals of Quetta, Pakistan. Centers of Fatmid foundation and Bolan Medical Complex hospital were included in studies. The target population was the guardians of patients attending different health facilities in Quetta Pakistan. Guardians of patients who visited Thalassemia Center for blood transfusion were included in the study. Guardian of the patients having age between 25-85 suffering with thalassemia major were included in the study. However, Patients taking oral iron overload treatment, suffering with some mental illness, or those who ae not willing or having any other chronic diseases are excluded from the study.

Study Sampling

Sampling Procedure & sample size

Non probability convenient sampling was adopted for data collection. A total of 327 respondents were selected for study. Out of which data of 73 were discarded due to incomplete filling/poor response. So finally data of 254 respondents were analyzed. The confidence level for calculating the sample size was considered 95% with 5% margin of error.

Data Collection Tool

Data collection tool was developed by research group pf University o Baluchistan Faculty Of pharmacy Quetta. It was a semi-structured questionnaire consisted of a total 25 questions the questionnaire was derived from the literature. Many research studies and reviews were selected and read for developing the questionnaire.

Questionnaire consisted of three sections, section 1 was about demographic detail of patients, section 2 depicted Thalassemia awareness questions, section 3 is about sources of information.

Experts evaluate it for face and content validity, forward and backward method was used for translation from English to Urdu and Urdu to English [6].

Ethical Approval, Informed Consent, Patient Privacy

Ethics committee of University of Baluchistan, Quetta approved the research study. Permission was also obtained from the Institutional heads or from any concerning authority of the institute. Any Information that can identify any respondent's identity is kept confidential.

Reliability Testing

Cronbach's alpha test was applied to check the reliability and internal consistency of items. The value of Cronbach's alpha for data collection tool was o.68 (number of items=38)

Data Analysis

Data analysis was done by SPSS version 20. Data was summarized by calculating descriptive statistics (Frequencies, Percentages, Mean, Median and Standard deviation). For inferential statistics Chi-square/Fisher exact test was applied. Chi square test was used to analyze any significant association between two categorical variables. Fisher Exact test was applied where the assumptions for chi square were not full-filled to analyze the categorical data. A P value less than 0.05 was considered as statistical significant.

Results

A cross-sectional questionnaire based study was conducted to assess the awareness regarding thalassemia in a thalassemia center at Quetta, Pakistan. A total of 327 respondents were interviewed on convenient basis. Data from 254 were analyzed 73 were discarded due to poor response/ incomplete filling. Descriptive statistics (Frequency, Percentage, Mean, Median and Mode) was used to summarize the data. Further chi-square was applied to find out the association between dependent and independent variables. Results of the study are mentioned in tabular and descriptive form

Demographic Details of Respondents

A total of 254 respondents were included in the current study, out of which 154(60.6%) were males while remaining 100(39.4%) were females. The respondents aged 25-85 were included in the study and maximum age was reported to be 45. Majority 193(76.0%) were married while 61(24.0%) were un-married. The majority 97(38.2%) had primary level of education while 35(13.8%) and 39(15.4%) were bachelor and master degree holders respectively. Majority of the respondents 174(78.55%) belonged to urban are while rest participating in study were from rural settings. (Table 1)

Table 1: Demographic details of respondents

Variable	Response N=254	Frequency	Percent
Gender	Male	154	60.6
	Female	100	39.4
Age	Below or equal to 25	58	22.8
	Below or equal to 45	157	61.8
	Below or equal to 65	37	14.6
	Below or equal to 85	2	0.8
Marital status	Married	193	76.0
	Single	61	24.0
Education level	Primary	97	38.2
	Middle	24	9.4
	Matric	35	13.8
	Intermediate	22	8.7
	Bachelor	35	13.8
	Masters	39	15.4
	Others	02	0.8
Occupation	Student	37	14.6
	Job	60	23.6
	Own business	66	26.0
	Others	91	35.8
Residence	Rural	80	31.5
	Urban	174	68.5

Assessment of respondent's awareness regarding thalassemia

Table 2 shows that all of the study participants 254(100%) were aware of the Thalassemia. Majority 242(96.9%) correctly stated that thalassemia occurs due deficiency in blood formation. Majority 236(92.9%) correctly stated that disease acquiring capability has no association with poor diet. Thalassemia has no genetic background was stated by almost 3/4th of the study participants. Interfamily marriages must be avoided as these lead to Thalassemia was stated by majority 186(83.2%) of the respondents. Thalassemia has no capability to spread from one person to other like was correctly stated by large proportion of the study participants 217(85.4%). Regarding diagnosis of the disease majority 213(83.9%) sated that it can be diagnosed by taking the blood sample of the patients while regarding diagnosis of disease via HB a small proportion 86(33.9%) was aware of this. More than half (67.7%) considered thalassemia to be curable/ treatable. Disease can be cured by utilizing medicines and transfusing blood to the patient was reported by less than half (48.8%) and 3/4th (76.4%) of the participants. About 3/4th of the respondents believed that surgery is the way of treating the thalassemia. More than 3/4th (80.3%) of the participants of the study stated that thalassemia patients face difficulty in their routine life. Less than half (36.3%, 41.7%, 39.8%) of the patients reported that thalassemia can lead to heart, liver and bone diseases respectively while more than (58.7%) stated that it can result in pathology in spleen. Thalassemia is life threatening infection was documented by majority of the patients 211 (83.1%).

Table 2: Assessment of respondent's awareness regarding thalassemia

Variable	Response	Frequency	Percent
Have you ever heard of Thalassemia?	Yes	254	100.0
	No	0	0.0
Is thalassemia is blood related disease?	Yes	246	96.9
	No	8	3.1
Is thalassemia is due to deficiency of blood formation?	Yes	242	95.3
	No	12	4.7
Is it a genetical disorder	Yes	187	73.6
	No	67	26.4
Is thalassemia due to poor diet?	Yes	18	7.1
	No	236	92.9
Is thalassemia due to an allergic reaction?	Yes	10	3.9
	No	243	95.7
Is thalassemia is transferable (from one person to other like other infections/germs)	Yes	37	145.6
	No	217	85.4
Inter family marriages may leads to thalassemia?	Yes	186	83.2
	No	68	26.8
The person having gene defect related to blood formation/thalassemia always have symptoms of disease?	Yes	45	17.7
	No	208	81.9
The person having gene defect related to blood formation/thalassemia may not have symptoms of disease?	Yes	57	22.4
	No	197	77.5
Diagnosis			
Thalassemia can be detected by taking blood samples of the patients	Yes	213	83.9
	No	41	16.1
Thalassemia can be detected by HB electrophoresis	Yes	86	33.9
	No	168	66.4
Treatment			
Is thalassemia is curable/treatable disease	Yes	172	67.7
	No	82	32.2
Can thalassemia be treated/managed by giving medicines	Yes	124	48.8
	No	130	51.2
Can thalassemia be treated/managed by giving blood to the patient	Yes	194	76.4
	No	60	23.6
Can thalassemia be treated managed by surgery	Yes	59	23.2
	No	195	76.8
Can thalassemia be treated/managed by bone marrow transplantation?	Yes	135	53.1

	No	119	46.9
Prognosis/Complications			
Person who have been diagnosed with thalassemia have problems in day to day life	Yes	204	80.3
	No	50	19.7
Person who have been diagnosed with thalassemia have problems in his/her social life	Yes	192	75.6
	No	62	24.4
Thalassemia leads to other diseases like diseases of heart?	Yes	92	36.2
	No	162	63.8
Thalassemia leads to other diseases like diseases of liver?	Yes	106	41.7
	No	148	58.3
Thalassemia leads to other diseases like diseases of bones?	Yes	101	39.8
	No	153	60.2
Thalassemia leads to other diseases like diseases of spleen?	Yes	149	58.7
	No	105	41.3
Thalassemia leads to other diseases like diseases of lungs?	Yes	88	34.6
	No	166	65.4
Can thalassemia leads to death?	Yes	211	83.1
	No	43	16.9

Note: All the frequencies and percentages are based upon observed values and missing values were excluded from analysis.

Information source

Health care providers were reported as major source of thalassemia information by more than 3/4th of the study participants while family/friends were reported to be the minor information source by the respondents, however, internet/books/literature and TV/radio were reported to be minor information source by the patients (table 3)

Table 3: Information source

Source of information	Frequency	Percent
Health care providers	194	76.4
Internet/Books/literature/Posters	55	21.7
T. v/ Radio	39	15.4
Family/Friends/Relatives	142	55.9
Others	30	11.8

Note: Respondents were allowed to choose more than one options

Comparison of mean knowledge score

Comparison of mean knowledge score was asses among demographics, it is showed that Education level, Occupation, Residence have significant difference (p<0.05) while other demographics Gender, Age, Marital status were not significantly associated (p>0.05) as shown in table 4.

Variable	Response N=254	Frequency	Mean	SD	P Value
Gender*	Male	154	15.35	5.217	0.946
	Female	100	15.53	4.739	
Age **	Below or equal to 25	58	15.00	5.311	0.836
	Below or equal to 45	157	15.62	4.931	
	Below or equal to 65	37	15.41	4.431	
	Below or equal to 85	2	17.50	0.707	
Marital status *	Married	193	15.72	4.770	0.251
	Single	61	14.73	5.269	
Education level **	Primary	97	13.82	4.521	0.001
	Middle	24	13.71	3.994	
	Matric	35	15.43	3.913	
	Intermediate	22	14.50	5.280	
	Bachelor	35	16.34	5.023	
	Masters	39	20.62	3.167	
	Others	02	11.00	1.414	
Occupation **	Student	37	16.49	5.215	0.001
	Job	60	17.20	5.602	
	Own business	66	15.35	4.201	
	Others	91	13.98	4.389	
Residence **	Rural	80	12.89	4.486	0.001
	Urban	174	16.64	4.668	

*Mean witney Test (p< 0.05)

** Kurskal-wallis (p<0.05)

Discussion

The current study was aimed to assess the awareness level of participants visiting thalassemia centers at Quetta, Pakistan. All of the study participants were aware of the thalassemia, the findings were similar to another study conducted in India, where almost all of respondents had ever heard of the Thalassemia [7].

Almost all of the study participants stated that thalassemia is blood disorder, the findings were far better than findings of

another similar studies conducted in Pakistan [8] and India where majority considered thalassemia a blood born disorder [7]. Thalassemia has capability to run through families.

In present study about 3/4th of the respondents were aware of the hereditary transfer of disease, similar findings were seen in in another study conducted in west Bengal [7]. In another study response was low in contrast to our study where more than half believed in genetic transmission of disease [9].

Thalassemia is a blood born infection that runs in the families but it doesn't tend to transfer from one person to another like other infectious agents like bacteria and viruses. In this study majority correctly stated that thalassemia is not a contagious disease, the findings were far better than those stated in another study conducted in Pakistan [8].

Inter families weddings must be avoided as the disease carries genetic background so premarital screening must be initiated to reduce the risk of infection. In the present study respondents majority were considered that inter family marriages increase the risk of catching infection, the findings were similar than another study where 70.9% were aware of the risk of thalassemia associated with inter families weddings [8]. In another study conducted in Sri Lanka 82% respondents were of the view that pre-marital screening must be done [10]

Thalassemia is not known to occur due to poor diet intake as in the current study majority of the participants correctly stated that diet has no role in acquiring the disease. In another study conducted in Malaysia presented poor response in this regard as only 40.4% believed that diet and thalassemia has no connection [11].

Thalassemia is a blood born disorder, it has not been attributed to any hypersensitivity reaction or allergic reaction but people consider that occurrence of allergic reaction can lead to hypersensitivity reaction. In the present study majority of the participants of the study correctly stated that thalassemia is not known to occur due to allergic reaction.

Thalassemia can be detected by taking blood sample of the patient or electrophoresis. In the present study majority of the respondents were aware of the diagnosis of Thalassemia by evaluating the blood sample of the patient, almost similar response was seen in another study where 82.6% documented that thalassemia can be diagnosed by taking blood sample of the patient [8]. Regarding electrophoresis more than half were unaware of this method of this diagnostic procedure, the finding of this study were found far better than another study where only 12.2% had familiarity with this method of diagnosis [12].

Regarding treatment availability less than 3/4th of the study participants considered that it's curable blood born infection, whereas in another study conducted in India males had more awareness than females in this regard [7].

Less than half of the participants believed that disease can be cured by taking medicines, poor response was noticed in another study where only 30.8% believed in curing thalassemia with use of medicines or undergoing surgical procedure [11].

Thalassemia cannot be cured by surgery as more than 3/4th of the study respondents correctly stated that surgery is the way of treating Thalassemia, while in another studies poor response was noticed in this regard [11].

Thalassemia is an illness that poses the patient to other life threatening illness but in the current study response in this regard was low. Whereas in another study better response was noticed than another present study [8].

The persons diagnosed with thalassemia cannot live a normal life as patient is always anemic and blood transfusion is mandatory which makes him/her to be bed ridden. About half of the study respondents stated that diagnosis with thalassemia renders the patient's life difficult but the in case of thalassemia minor the patient may have a healthy life after treatment as in a study more than half demonstrated that thalassemia minor may lead a patient to a healthy life [8].

Education is important determinant of individual's knowledge; education modifies the way of perceiving the things, attitude and behaviors. A highly educated person usually depicts better knowledge. In the present study educated individuals presented better knowledge response as education in important determinant of health like health behaviors. Education is important mechanism that enhances individuals' health and also influence their ability of well-being. Those who would have more years of schooling will tend to have better health behavior and well-being [13].

The present study was performed to access the awareness regarding the thalassemia diseases. Results of the study concluded that the people of Quetta had inadequate level of awareness regarding the thalassemia disease, it's mode of transmission, diagnosis and treatment. People are generally aware about its prognosis and mortality. However, a significancy of awareness found to be increased with the level of education.

Conclusion

The results of the present study concluded that the people of Quetta had adequate level of awareness regarding the thalassemia disease, it's mode of transmission, diagnosis and treatment. People are generally aware about its prognosis and mortality. However, awareness was found to be increased with increase in level of education.

Recommendations

This study suggests a number of recommendations.

Recommendations for Policy Makers

- People are generally aware about Thalassemia but on main issues there is still lack of awareness. So on the basis of the current study it is strongly recommended that there should be proper awareness among the people.
- Government should conduct educational and awareness programs and campaigns to improve the awareness among people regarding thalassemia.
- Health campaigns should be organized to assist patients and caregivers to cope better with thalassemia.
- The government and school officials should make such policies to improve school functioning of thalassemia patients. Moreover, they should be supported financially.

Recommendations for Practice

- In light of the above results, it is recommended that thalassemia children and their caregivers should be given lifetime psychological assistance to prevent mental issues.
- Cognitive Behavioral Therapy can be beneficial

psychological strategy to increase compliance with treatment, reducing emotional load of disease and enhancing quality of life of children with thalassemia and their caregivers.

Recommendations for future Research

- It is also recommended to conduct this study in other areas of Pakistan in order to obtain a close picture of the actual situation.
- Future researchers can use this study as a standard to compare the results of their study to assess the improvement in HRQoL of thalassemia patients.
- Multi-centered study needs to be conducted to thoroughly assess HRQoL of thalassemia patients as this study was conducted in one thalassemia center only.

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