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An Analysis of Experiences and Problems of Parents with Thalassemia Children

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ABSTRACT

This study is mainly concerned with attaining a better understanding of the predicaments and hurdles that parents of Thalassemia patients experience. This study was conducted within the region of Lahore and contains data about the parents of Thalassemia patient's experiences. This study mainly collected data from 150 respondents. The respondents were parents of those Thalassemia patients who attended Sundas Foundation for regular blood transfusions. An interview schedule was employed for collecting data from the respondents concerned. The findings of the research indicated that lower the age of the patients, the greater will be the depression among thalassemia patient's parents. The results further indicated the severe affect thalassemia has on children in the 1 to 5 years age bracket. The level of depression was greater in those parents that had a male child suffering from Thalassemia. Also, those parents with lower incomes experienced greater depression than the ones having mid to high levelled incomes. The children with Thalassemia were indeed a cause for parental depression. This study emphasizes a profound need for better-educating parents about thalassemia and how it impacts the lives of their children as well as their own. This study suggests that preventive measures like Chronic Villas Sampling Test and HB Electrophoresis during pregnancy could be adopted.

Keywords
Thalassemia children, experiences and problems of parents, strategies for prevention

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Introduction

Thalassemia has emerged as a prominent and egregious problem in the modern world. This malady is a most pervasive and eminent disorder and is hereditary. This disease also evinces ramifications on the socio-economic structure of the family as a unit while Thalassemia is regarded as a grievous predicament all across the globe, its effects are palpably distinctive in countries like Iran, India, Greece, and Pakistan especially (Ghafoor, 2016). Thalassemia is a chronic disease that adversely affects the human body. This is an inherited disease that leads to a disorder of the hematological sort in the human body. Thus, this disease culminates in anemia and requires perennial medical treatment throughout the patient's lifespan (Kandhro et al. 2017).

One of the consequences that thalassemia entails is emotional distress and unrest in the patient's life (Maheen et al. 2015). There are three types of Thalassemia from a medical perspective. They can be enumerated as:

- Thalassemia Major
- Thalassemia Intermedia
- Thalassemia Minor

The main cause of Thalassemia is the mutation that a subject inherits through marital bonds. This disease can be controlled and limited by regular and timely transfusions of blood. Iron chelation therapy can be effective as well. However, it is best if the patient is sensitized about his/her predicament at an early age (Din et al. 2014). The unfortunate fact is that this disease is often mishandled on a clinical basis. This can be attributed to a lack of resources and sagacity on part of the patient about the disease. Among the many detrimental effects of Thalassemia, financial loss, emotional disorder, social disturbance is especially prominent (Ishaq et al. 2012). Also, the task of having the patient's hemoglobin, iron, and Red Blood Cells proves to be extravagant in terms of expenditure. The brunt of these problems is

inexorably borne by the parents of thalassemia patients (Pakbaz et al. 2005).

Many notable steps have been initiated by the Pakistani Government and competent authorities for bringing about mitigation in this deadly disease. However, there is much that still needs to be done in this sector (Asif & Hassan, 2016). Currently, the number of institutions that are dedicated to the controlling and remedying of Thalassemia is very low. There are currently 7 million children afflicted with Thalassemia in Pakistan. This figure is inclusive of those subjects that exhibit symptoms of the ailment in question (Sayani & Kwiatkowski, 2015). Therefore, there is a profound need for introducing workable and effectual measures at the root level. That is because the picture of thalassemia in Pakistan is very bleak. For instance, the number of thalassemia homozygotes that manifest in Pakistan exceeds 5000 and 6% of thalassemia cases emerge as a result of irregular hemoglobin creation (Ishaq et al. 2012).

A step that can be incredibly potent in rooting out thalassemia and alleviate its statistics within Pakistan is testing before marriage. But due to ignorance and stigma surrounding this disease this test isn't conducted as frequently as required. Still, it would be a better alternative to bringing about a nascent life in this world that will require perpetual dependency, blood transfusions, etc. (Sattari et al. 2012). A patient of thalassemia will have to cope with a constant battle for survival and life will certainly be difficult. The latter will be marked with adversity, in health and social functioning. That is why concrete steps need to be initiated towards stemming or at least containing this heinous ailment (Kermansaravi, Najafi, & Rigi, 2018).

Objective of the Study

The main objective upon which this research is predicated is the relationship between parents and their children that have been affected with Thalassemia. The resultant depression in patients in regards to monetary problems and accruing of pertinent information were also gauged.

Methodology

The pertinent data for this study was gathered from a sample of 150 parents of Thalassemia patients. These 150 patients were selected from a total count of 200 parents of patients that were patrons of Sundas Foundation. The remaining of the 50 parents didn't give consent for joining in this study. They were mainly unwilling and were perturbed by the critical condition of their patients. The questionnaire survey was employed collect the data from the respondents. Two organizations dealt with providing blood transfusions to patients at the time of data collection. They were Sundas and Fatimid Foundations and the patients visiting these organizations. Both of these organizations were approached for the collection of data. However, only Sundas Foundation accorded permission for the collection of data from their subjects. That is why, the data evinced by this study is mainly acquired from the parents of patients that visited Sundas Foundation. For the analysis of the collected data SPSS software was utilized. General Linear Model (GLM) and Bivariate Regression (BR) test were applied for a detailed analysis of data collected from respondents.

Results, Findings & Discussion

The average age of respondents was 26 to 30 years. The majority of respondents had a secondary level of education. 38.7 percent were doing a job in which the majority were living in a nuclear family structure. 45.3 percent have 6-10 family members and earnings 10000-20000 per month income. The majority of the respondents were residing in urban areas.

Table 1: Logistic Regression between Parental Depression and Children Age

An Age group of thalassemia child	B	S.E.	Wald	Df	Sig.	Exp (B)	95% C.I. for EXP(B)	
							Lower	Upper

Step 1[a]	The age group of Children (1-5)			15.657	4	.004			
	(6-10)	-1.190	.815	2.129	1	.145	.304	.062	1.504
	(11-15)	-1.617	.865	3.496	1	.062	.199	.036	1.081
	(16-20)	-1.792	1.006	3.173	1	.075	.167	.023	1.197
	(21-25)	1.764	1.085	2.644	1	.104	5.833	.696	48.873
	Constant	-.847	.690	1.508	1	.220	.429		

Thus, aforementioned table results indicate that those children who have age group category (1-5) has key important (P < 0.05) relationship with level of depression among parents whereas the other children who have age group category (6 - 10) (11-15) (16-20) have not any significant relationship with parent's level of depression.

Table 2: Logistic Regression between Parental Depression and Child Gender

		B	S.E.	Wald	Df	Sig.	Exp (B)	95% C. I. for EXP (B)	
								Lower	Upper
Step 1[a]	Gender of Child	2.169	1.043	4.325	1	.038	8.753	1.133	67.627
	Constant	-3.714	1.012	13.462	1	.000	.024		

Findings of the above table 2 describes parental depression regarding to gender of the child in which female child of thalassemia was compared to male thalassemia children. The study results show a significant (P < 0.05) association on depression level of parents with male children comparatively female thalassemia child.

Table 3: Logistic Regression between Parental Depression and Pertinent Profession

	Profession	B	S.E.	Wald	Df	Sig.	Exp (B)	95% C.I.for EXP (B)	
								Lower	Upper
Step 1	Handcrafting			5.739	4	.219			
	Farming	20.258	14210.361	.000	1	.999	.000	.000	
	Job	-1.022	.601	2.889	1	.089	.360	.111	1.169
	Own business	-.742	.660	1.264	1	.261	.476	.131	1.736
	Labor	-2.351	1.112	4.475	1	.034	.095	.011	.841
	Constant	-.944	.445	4.496	1	.034	.389		

Findings of the above table 3 describe the parental depression with relation to their profession. In view of this, results of the research showed that all other categories of the profession were compared with handcrafting job category in which logistic regression results indicates that the labor profession has significant relationship (P < 0.05) with parental depression.

Table 4: Multivariate Tests

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.801	280.395[b]	2.000	139.000	.000
	Wilks' Lambda	.199	280.395[b]	2.000	139.000	.000
	Hotelling's Trace	4.034	280.395[b]	2.000	139.000	.000
	Roy's Largest Root	4.034	280.395[b]	2.000	139.000	.000
Awareness of thalassemia	Pillai's Trace	.074	5.529[b]	2.000	139.000	.005
	Wilks' Lambda	.926	5.529[b]	2.000	139.000	.005
	Hotelling's Trace	.080	5.529[b]	2.000	139.000	.005
	Roy's Largest Root	.080	5.529[b]	2.000	139.000	.005
Age of Child	Pillai's Trace	.079	1.434	8.000	280.000	.182

	Wilks' Lambda	.922	1.449[b]	8.000	278.000	.176
	Hotelling's Trace	.085	1.464	8.000	276.000	.170
	Roy's Largest Root	.081	2.846[c]	4.000	140.000	.026
Gender of Child	Pillai's Trace	.037	2.675[b]	2.000	139.000	.072
	Wilks' Lambda	.963	2.675[b]	2.000	139.000	.072
	Hotelling's Trace	.038	2.675[b]	2.000	139.000	.072
	Roy's Largest Root	.038	2.675[b]	2.000	139.000	.072
Age of Child * Gender of Child	Pillai's Trace	.023	.536	6.000	280.000	.781
	Wilks' Lambda	.977	.533[b]	6.000	278.000	.783
	Hotelling's Trace	.023	.531	6.000	276.000	.785
	Roy's Largest Root	.019	.903[c]	3.000	140.000	.441

*a. Design: Intercept + Awareness of thalassemia + Age of Child + Gender of Child + Age of Child * Gender of Child*
b. Exact statistic
c. The statistic is an upper bound on F that yields a lower bound on the significance level.

Findings of above table 4 indicates that thalassemia disease related awareness has a strong association ($P < 0.05$) with parental depression and economic situation of the parents. Whereas other variables like gender and age of the thalassemia children has no significant relationship ($P > 0.05$) with parental depression and economic condition of the parents.

Table 5: Tests of Between-Subjects Effects

Source	**Dependent Variable**	**Type III Sum of Squares**	**Df**	**Mean Square**	**F**	**Sig.**
Corrected Model	Level of depression among parents	117.039[a]	9	13.004	3.553	.001
	Economic cost of thalassemia	82.232[b]	9	9.137	1.277	.254
Intercept	Level of depression among parents	1702.013	1	1702.013	464.999	.000
	Economic cost of thalassemia	1420.640	1	1420.640	198.564	.000
Awareness of thalassemia	Level of depression among parents	40.492	1	40.492	11.063	.001
	Economic cost of thalassemia	1.110	1	1.110	.155	.694
Age of Child	Level of depression among parents	37.097	4	9.274	2.534	.043
	Economic cost of thalassemia	5.167	4	1.292	.181	.948
Gender of Child	Level of depression among parents	14.933	1	14.933	4.080	.045
	Economic cost of thalassemia	16.604	1	16.604	2.321	.130
Age of Child * Gender of Child	Level of depression among parents	2.046	3	.682	.186	.906

	Economic cost of thalassemia	17.713	3	5.904	.825	.482
Error	Level of depression among parents	512.435	140	3.660		
	The economic cost of thalassemia	1001.641	140	7.155		
Total	Level of depression among parents	22785.000	150			
	The economic cost of thalassemia	26773.000	150			
Corrected Total	Level of depression among parents	629.473	149			
	The economic cost of thalassemia	1083.873	149			

a. R Squared = .186 (Adjusted R Squared = .134)
b. R Squared = .076 (Adjusted R Squared = .016)

The aforementioned table 5 shows an explicit association between awareness of thalassemia and parental depression levels ($P < 0.05$). Likewise, the gender of the thalassemia patient and parental depression levels also have a strong association ($P < 0.05$). However, no such association exists between the economic condition of parents and the age/gender of the thalassemia patient ($P > 0.05$).

The findings of this research describe that the awareness level of thalassemia imparts no effect on depression levels felt by parents of patients. Also, the study conducted by Kevyan et al. (2009) assessed the relationship of thalassemia with mental depression and its effect on health support and corroborate the findings garnered as a result of this study. Another development that was uncovered through this study was that the age of thalassemia patients also impacts and influences the depression levels exhibited by their parents. The lower the age of the patients, the greater will be the depression that they evince. This finding is also supported by the study conducted by Pakbaz et al. (2010). The latter verifies the severe affect thalassemia has on children in the 1 to 5 years age bracket.

Another finding from this study is that the level of depression experienced by parents with the white-collar occupation is considerably lower in contrast to the one felt by those having adopted lower and manual labor-based jobs. This is in direct congruence with the findings of the study conducted by Saxena et al. This study asserts that those people who are employed in white-collar jobs and are reasonably educated will have a better understanding of thalassemia and its adverse effects. It shows that 96% of such parents will be better equipped for facing the trials and tribulations that being a parent of a thalassemia patient entail. Hence, the level of depression that they experience will also be lower. That is because they comprehend the disease better and have a workable grasp of the strategies needed for dealing and preventing this disease. Incidentally, these strategies ascribe to ones such as blood screening tests, genetic counseling, married women pregnancy test, etc.

On the other spectrum, this study also shows that those parents that are engaged in low income and manual labor-based jobs show heightened levels of depression and stress. This can be attributed to a lack of knowledge and ignorance of the techniques that can be adopted for dealing with Thalassemia. This finding is in synch with the study of Liem et al (2011). This study also shows that the living standard of parents and the depression that they feel over the condition of their thalassemia afflicted children are profoundly intertwined.

Conclusion

This study showed conclusive evidence that those parents have a higher level of depression whose children are afflicted with thalassemia in the early years. Parents usually possess less, and frankly impotent, knowledge about what the disease of Thalassemia evinces. They are ignorant about its severity, the many grievous repercussions that it

entails and the considerable stress and depression that follows. This usually is the scenario when the thalassemia patient is lower than 5 years in age. However, once the symptoms become more pronounced, the parents start to dart and dash about. This results in doing more harm than good and is often detrimental for them and their children.

Interestingly, another prominent detail is that the gender of thalassemia patients also affected the depression level exhibited by their parents. If it was a girl with thalassemia, then yes, the depression, the stress was there. However, when the afflicted was of the male gender then the rage, the anguish, the depression was almost palpable. It yields the conclusion that parents act more concerned, more focused and perturbed when the child suffering from Thalassemia is a male. This is in direct vindication of the popular male-dominant ideology that has permeated the fabric of Pakistani society on a ubiquitous level.

This study also showed that the significance of education can't be undermined when it comes to battling Thalassemia. That is because it was uncovered during this study that those parents with sufficient and adequately appropriate levels of education were able to better counter thalassemia. That is because an educated individual will be able to better perceive and practice protective and preventive measures related to Thalassemia. However, an uneducated person has no effective understanding or skills necessary for coping with thalassemia. That is why they are usually beset by depression and stress on a grander scale in contrast to more educated and literate persons. These people are unacquainted with the requirements of disease management.

The media should also play its role in promulgating awareness amongst the general public about this disease. They should also disseminate the preventive and control measures required for Thalassemia so that people may have a better chance of handling this disease. Also, the blood donation drive must be enhanced and improved so that those facing thalassemia might receive their transfusions in a timely and punctual manner.

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