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Role of Non-governmental Organization in Improving Socio-economic and Physical Conditions of the Patients of Thalassemia and Hemophilia

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Abstract: The prime objective of the study was to investigate the role of non governmental organization (Ali Foundation) in improving socio-economic and physical condition of the patients of thalassemia and hemophilia the study was examine the problems faced by the patients. 100 respondents were selected from Ali foundation. Well designed questionnaire consisting of structured as well as nonstructured questionnaire was used in this study we explore the research objective. The appropriate statistical techniques such as descriptive and inferential statistics were used for data analysis.

Key Words: Non - governmental Organization, Socio - Economic and Physical Conditions and Thalassemia

Introduction

Ill Health is universal problem effecting both the individual and society. No society leaves the responsibility for maintaining health and treating ill health entirely to the individual. With the advancement of technology, a number of diseases have been discovered. In the present days blood disease like, blood cancer, thalassemia, hemophilia, hepatitis etc. are common chronic diseases. Blood is one of six major forms of tissue in the body.

Human blood contains three types of elements.

- Red blood cells
- White blood cells
- Platelets.

Red blood cells transport oxygen from the lungs to body tissues. In an adult male there are usually about five million red blood cells per cubic millimeter or about 82 billion in one cubic inch. The normal red blood cells for woman are usually 82 billion or about 4500000 per cubic millimeter of blood. The white blood cells perform the function to fight off disease. In adults there are 5000 to 10000 white blood cells, while in infants the number is double. The tiny elements called "platelets" help in forming clots and repair the blood vessel wall. The focus of the present study is on thalassemia and hemophilia. These are major blood related diseases. These are inherited diseases and require regular treatment, love and affection.

Thalassemia: Thalassemia is a group of genetic blood disorders that affect a person's ability to produce hemoglobin. Hemoglobin is the protein in our red cells, that carries oxygen and nutrients to all parts of the body. In general, thalassemia can be divided into two main types (i) alpha thalassemia and (ii) beta thalassemia.

People who do not produce enough alpha protein have alpha thalassemia and people who do not have enough beta protein have beta thalassemia. Within each type, There are three classifications.

- Thalassemia minor
- Thalassemia intermediate
- Thalassemia major

A person with thalassemia minor will experience no-significant health problems. Thalassemia intermediate is an intermediate form of disease which require, regular cure by a doctor. In alpha major thalassemia, there are no alpha jeans in the individual's DNA. Most individuals within this condition die before or shortly after birth. Thalassemia major is a serious disease. Which require life long blood transfusion and medical care.

Beta Thalassemia: In beta thalassemia major, there is complete lack of beta protein in hemoglobin that require regular blood transfusion. This life long blood transfusion lead to iron over load which must be treated with chelation therapy to prevent early death from organ failure.

Beta Thalassemia Major: A children who has beta thalassemia major, if untreated can experience several or all of the following. Severe anemia jaundice, an enlarged spleen fatigue listlessness, reduced appetite, enlarged and fragile bones identifiable finical malformation, growth problem. In most severe cases untreated children will die from severe anemia. Those who receive early transfusion regimen and iron removal therapy can avoid many of these symptoms.

Beta Thalassemia Minor: In beta thalassemia minor lack of beta protein is not greater enough to cause problem in normal functioning of hemoglobin. A person in this condition experience no health problems.

In alpha major thalassemia and beta major thalassemia life long brod transfusion lead to iron over load. The heart lover, lungs can not work properly.

The excess Iron be Removed: The only drug currently available for treatment of iron over load is desferrioxamine (brand name desferal) this therapy has two major drawbacks.

The expenditure for desferal therapy works out to Rs. 13500/- per month. This infusion pump is also imported and costs Rs. 20,000/- Most thalassemics can not afford this high cost of treatment and usually before they reach the age of 15-20 years.

Bone Marrow Transplantation: The only curative treatment for Thalassemia is a bone marrow transplantation this procedure is very expensive costing several lakhs of rupees. Even more critical is the difficulty in getting a fully compatible donor.
This procedure destroys a patients blood farmintg tissue and replaces it with donor tissue that produces normal amount of hemoglobin. The most likely donors can be of brother or sister of the Thalassemic patient. In Pakistan it can be complete just in to lakhs heat problem, liver problem, Endocrine problem and skin problem can be faced by Thalassemic patient.
Hemophilia: Hemophilia is a genetically inherited disorder of the blood clotting system, over 50 substances are needed for blood to clot. If one of the substances is missing or the amount of substance is too low, the person may bleed spontaneously or blood excessively when trauma occurs. Depending on which factor is missing or too low, there are two main types of hemophilia

- Hemophilia A.
- Hemophilia B.

Hemophilia A: It is also known as "Factor VIII deficiency" and classical Hemophilia" patients with hemophilia, A do not have enough factor VIII. In 90 percent of the patients of hemophilia, have efficiency of factor VIII.
Hemophilia B: It is also known as factor IX deficiency. Another name for hemophilia B is "Christmas disease" patients with hemophilia B do not have enough factor IX. Both types of hemophilia are present in either a severe, moderate form. Hemophilia occurs in about 1 for 10,000 individual. All types of hemophilia are present in either a severe, moderate. All forms and severities of hemophilia can be treated.
The gene for hemophilia is carried on X chromosome. Males have an X chromosome and on Y chromosome. The X chromosome comes from the mother and Y chromosome comes from father. If the mother has a defective gene, the sons, chance of hemophilia is 50 percent, depending on which chromosome is inherited. A son can not inherit the disorder from his father, over if the father has hemophilia.
In case of daughter, one X chromosome came from mother and other X chromosome is of Father. The daughter also has a 50 percent chance of becoming a carrier, if the mother is a carrier, depending on which X chromosome is inherited.
Women with hemophilia gene are called carriers. Each daughter of a carrier mother has a 50 percent chance of being a carrier. Each son has a 50 percent chance of having hemophilia. In small children with this disorder, serious and dangerous bleeding is mostly related to simple task like crawling and walking. Joints are the most common sites of bleeding.
Gene therapy is a suggested method of treatment for this disorder. The process consists of getting multiple copies of the deceived gene into modifying the clothing factor and getting efficient amount in to the blood stream. The clotting factor agents are packaged and freeze dried form before they are infused into the patients.

Thalassemia and hemophilia are major blood related and inherited diseases which require regular transfusion of blood/plasma. Due to these diseases many problems are faced by the patients like weakness and some times pain. Many social and economic problems are faced by parents of patients. In many families more than one children are suffered from these diseases and they face a permanent problem of tension. General people are not aware of these diseases and people do not try to take any test during pregnancy. So as a student of sociology I design to study the problems of patients and their families, and to study the factors which become the cause of thalassemia and hemophilia.
The present study was conducted with the following objectives.

- To find out the basic characteristics of the respondents/respondent's families.
- To investigate the problems faced by the respondents and respondents families.
- To examine the role of organization for the welfare of the patients.
- To give some suggestions for the improvement of the patients of non government organization.

Hasan (2001) said that Thalassemia is a inherited disease. Death from Thalassemia major can be delayed but not averted. Screening for carriers now available in Pakistan and it will be useful to have this done before the final commitment for a marriage takes place and if it is detected after marriage that both the parents are carriers. The pregnant women must be taken and tested. If the child is suffering from Thalassemia major. Then pregnancy must be terminated if the test has negative results. The pregnancy is allowed to continue as the new born child will be free from this condition.
Shamem Ara (2001) said that inherited diseases can be over come. Mothers, must have test during pregnancy. If there is any patient of hemophilia in relatives than cousin marriage in relatives should be ignored. In hemophilia disease women are carrier and they transfer it to their sons.
Yasmin Rashid (2001) said that Thalassemia is an inherited disease. She said that proper care should be given to the patients of thalassemia. This would help them to become useful and effective citizen. She said that patients of Thalassemia major require regular blood transfusion but Thalassemia minor has less prominent symptoms.

Materials and Methods

The main objective of this chapter is to explain various tools and technique employed for the collection analysis and interpretation of data, related to the study under investigation.
Universe: The universe of the present study comprised of the parents of the patients (children) who come to get treatment for their children from Ali-Zaib transfusion center in Faisalabad.
Profile of Ali Foundation: Ali foundation is a non government health organization which is working on Thalassemia and hemophilia. This institution is the hope of life for the patients and this brought hope for those who were hopeless from the lives of their children blood

related expenditures are provided by some kind persons because this sorrow or misery is not of such children and their parents but it is the misery of human beings.

Mr. Muhammad Ali was the founder of Ali-foundation. This organization is also working in Lahore called Fatmeed Angeo. Such institutions are also working in Karachi, Sargodha, and Peshawar.

In Faisalabad this institution is working from October 12, 1995. It is situated in Lasani Town Faisalabad.

Sample: Data was collected by 100 respondents who used to visit the organization to get treatment for their children during one to two weeks whose children were suffered from thalassemia and hemophilia. During this period 102 patients were treated by Ali-Zaib foundation. All the respondents were interviewed but only two respondents refused to give proper information, so sample size remains 100. A sample of 100 percent of the patients of hemophilia and Thalassemia were taken by convenient method.

Table 1: Percentage Distribution of the Patients with Regard to Suffering in Thalassemia and Hemophilia

Suffering in	F	% age
Thalassemia	67	67.0
Hemophilia	33	33.0
Total	100	100.0

It is clear from the Table 1 that majority of the patients i.e. 67% suffering in thalassemia, while remaining 33% were patients of hemophilia.

Results and Discussion

Table 2: Percentage Distribution of the Respondents Regarding to Their Age, Sex, Education and Monthly Income of Their Families

Age (year)	F	%age
Less than 30	42	42.0
31-40	28	28.0
40 and above	30	30.0
Total	100	100.0
Sex	F	%age
Male	28	28.0
Female	72	72.0
Total	100.0	100.0
Educational level	F	%age
Illiterate	35	35.0
Primary	18	18.0
Middle	8	8.0
Matric	23	23.0
Intermediate	12	12.0
Graduation	4	4.0
Total	100	100.0
Income RS	F	%age
Less than 3000	51	51.0
3001-6000	37	37.0
6001 and above	12	12.0
Total	100	100.0

Mean age of the respondent = 34.20 years

The Table 3 shows that 80.3 percent of the brothers and sisters of those patients whose parents were married with their cousin were not diagnose hemophilia, while 19.8 percent were diagnosed by this diseases 70 percent of the brothers and sisters of those patients whose parents were married in far relatives were free from this diseases, while 25 percent of them were suffered from hemophilia. Patient of the parent whose marriage was held out of family, 92.3 percent of their brothers and sisters were not suffered from hemophilia, while 17.07 percent of them were suffered from this diseases.

Value of χ^2 is 6.7360 shows that there is non-significant association between parent marriage and brothers and sisters of the patients who were diagnosed by hemophilia.

From the above Table 4 it is clear that 73.2 percent of the brothers and sisters of the patient was not suffered from thalassemia while 26.8 percent were suffered from this diseases. 81.3 percent of the brothers and sisters of those patients, whose parents were married in far relatives, were not suffered in this family where as 18.75 percent were diagnosed in this disease.

Those patients, whose parents were married out of family, their 76.9 percent brothers and sisters were not suffering from thalassemia, while 23.1 percent of them were suffering from this type of blood disorder.

The value of χ^2 shows a non-significant association between parents marriage and brothers and sisters of the patients who were diagnosed by thalassemia.

Table 5 reveals that 23.3 percent respondents were satisfied to great extent and 76.7 percent were satisfied to some extent with the blood facility that center provides to the patients of thalassemia. 52.9 respondents who come to get treatment for hemophilia were much satisfied with the provision of plasma and 47.1 percent were satisfied to some extent with this facility. Majority of the respondents IE. 80 percent were satisfied to some extent and 20 percent were much satisfied with the provision of free medical facilities.

Calculated value of χ^2 is 7.10445 and if is 2. It is clear from the Table that there is significant association between the provision of facilities and respondents satisfaction with these facilities.

Table 6 shows that 66 percent illiterate or primary pass respondent are much satisfied with the facilities and 34 percent are satisfied to some extent 77.4 percent respondents with educational level of middle and matric pass are satisfied to great extent with the facilities that organization provides for the treatment of the patient and respondents i.e. 77.4 percent with educational level middle or matric are satisfied to great extent and 22.6 percent are satisfied to some extent 87.5 percent respondents with intermediate or above level of education are much satisfied and 12.5 percent respondent are satisfied to some extent with the provision of facilities.

Calculated value of χ^2 is 3.30736 shows non significance association between education of the respondents and the provision of the facilities.

Table 7 reveals information about the facilities available to the patients at the organization. 43 percent of respondents reported that at organization free blood facility was available. Those respondents who mentioned the availability of free medical facilities were 40 percent. While 17 percent told about free availability of plasma facility. Majority of the respondents i.e. 73 percent were satisfied to a great extent with the facilities available at the organization, where as those respondents who were satisfied to some extent with the available facilities at

Table 3: Association Between Parents Marriage and Brothers and Sisters of the Patients Who Were Diagnoses by Hemophilia

Parents marriage	Brothers and sisters of the patient diagnosed by hemophilia.		
	No.	Yes.	Total
Cousin marriage	(80.3) 57	(19.8) 14	(71.0) 71
For relatives	(75.0) 12	(25.0) 4	(16.0) 16
Out of family	(92.3) 12	(7.7) 1	(13.0) 13
Total	(71.0) 71	(17.07) 17	(10.0) 100

χ^2 cal = 6.73606 , DF = 2 Significant = .3459

Table 4: Association Between Parents Marriage and Brother's and Sister's of the Patients Who Were Diagnosed by Thalassemia

Parents marriage	Brothers and sisters of the patient diagnosed by a thalassemia		
	No.	Yes	Total
Cousin marriage	(73.3) 52	(26.8) 19	(71.0) 71
For relatives	(81.3) 13	(18.75) 3	(16.0) 16
Out of family	(76.9) 10	(23.1) 3	(13.0) 13
Total	(75.0) 75	(25.0) 25	(10.0)100

χ^2 cal = 3.62684, DF = 2, Significant = .9342

Table 5: Association Between Facilities That Organization Provides and Satisfaction of the Respondents with These Facilities

Facilities	Satisfaction with the facilities		
	To some extent	To great extent	Total
Blood	(76.7) 83	(23.3) 10	(43.0) 43
Plasma	(47.1) 8	(52.9) 9	(17.0) 17
Free Medical facilities	(80.0) 32	(20.0) 8	(40.0) 40
Total	(73.0) 73	(27.0) 27	(10.0)100

χ^2 = 7.10445, DF = 2 , Significant = .0287

Table 6: Association Between Education of the Respondents and Satisfaction with the Facilities That Organization Provides

Educational level	Satisfaction with the facilities		
	To great extent	To some extent	Total
Illiterate	(66.0) 35	(34.0) 18	(53.0) 53
Middle	(77.4) 24	(22.6) 7	(31.0) 31
Intermediate +	(87.5) 24	(12.5) 2	(16.0) 16
Total	(73.0) 73	(27.0) 27	(100.0) 100

χ^2 3.30736 DF = 2 Significant = .0000

Table 7: Percentage Distribution of the Respondents Regarding the Facilities Provided by the Organization, Level of Satisfaction with the Facilities, Regarding the Attitude of Staff of Center to Wards Patients, Satisfaction with the Environment of the Organization

Facilities	F	%age	Satisfaction Level	F	%age	Attitude of the staff	F	%age	Satisfaction With the Environment	F	%age
Free Blood facility	43	43.0	To a great extent	73	73.0	Good	85	85.0	Yes	100	100.0
Free plasma facility	17	17.0	To some extent	27	27.0	Normal	15	15.0	No	-	-
Free Medical facilities (Blood tests)	40	40.0	Not at all	-	-	Bad	-	-			
Total	100	100.0	Total	100	100.0	Total	100	100.0	Total	100	100.0

organization were 27 percent according to a large number of the respondents i.e. 85 percent, attitude of staff towards patients was good, while remaining 15 percent stated the attitude of staff towards patients was normal. Table reveals that all the respondents i.e. 100 percent were satisfied with the environment of the organization.

Findings: Majority of the patients i.e. about 50 percent were of age group 1-2 years. A major proportion of the respondents i.e. 35 percent were illiterate. A large number of the respondents had monthly income less than 3000 from all resources. Majority of the fathers of the patients i.e. 31 percent were matriculate. A major proportion of the mother's of the patient's i.e. 38 percent were illiterate. A simple majority of the respondents i.e. 54 percent reported that they were living under nuclear family system. A simple majority of the respondents i.e. 58 percent had pacca houses. In the houses of 76 percent of the respondents, there were 1-3 rooms. Majority of the respondents i.e. 88 percent had their own houses where as remaning12 percent were living in rented houses. 76 percent of the parents of the patients were married with their cousin. Majority of the patients i.e. 67 percent were suffered in Thalassemia, while the remaining 33 percent were patients of hemophilia. All the patient of Thalassemia were suffering from Thalassemia major one third of the patients of hemophilia (66.7 percent) were suffered in hemophilia major. A large number of the patients i.e. 81 percent were suffering from disease since birth. In majority of the patient i.e. 64.2 percent Thalassemia was diagnosed by test. Age of 53 percent of the mothers of the patients at the time of pregnancy was between 18-24 years. A majority of the mothers i.e. 95 percent had no test during pregnancy. In 86 percent of the patients Thalassemia and hemophilia were diagnosed with in one year of the delivery. In majority of the patients of Thalassemia i.e. about 64 percent and 15 percent of the patients of hemophilia visit the center for transforming blood/plasma after 15 days and patients of hemophilia minor come to the organization for getting treatment after long duration. A large number of patients i.e. 78 percent had to face no complications in the process of transforming plasma/blood while 22 percent of them had to face the problem of fever and vomiting during the process of transfusion. Half of the respondents i.e. 50 percent were sending their children to organization for 1-3 years for treatment. Majority of the respondents i.e. 62 percent said that they were giving normal food to the patients. A major number of the patients i.e. 98 percent used to tape medicine whenever they suffered from any other disease and that medicine had no side effects for them. About 70 percent class fellows of those patents who were going to school had good behaviour towards them. Majority of the members of the society that is 72 percent and 52 percent of friends of the patient had good behaviour towards the patients. 63 percent of the respondents told that the behaviour of family members towards patients (children) was loving. A major proportion of the patients i/e. 56 percent had 2 brothers and sisters who were also diagnosed by Thalassemia. A vast majority of the respondent i.e. 95 percent stated that the staff in the center was highly qualified. Majority of the respondents i.e. 85 percent said that the attitude of the staff towards patients was good. All the respondents had no complain against the staff of center. It was found that the treatment in the organization (Ali Zaib blood foundation) was free. 54 percent of the respondents said that they had to face tension and financial problems due to the disease of their children. All the respondents were satisfied with the environment of the organization. Majority of the respondents i.e. 73 percent were satisfied to a great extent with the facilities available at the organization. A major proportion of the respondents reported that they had to spend 100-300 rupees while coming to organization and 12 percent were those whose expenditure was 600 Rs and above. All the respondents said that the organization was not providing any skill training to the patients. There is non-significant association between parent's marriage and brothers and sisters of patients who were diagnosed by hemophilia. There is non-significant association between parent's marriage and brothers and sisters of patients who were diagnosed by thalassemia. There is significant association between the provision of facilities and respondent's satisfaction with these facilities. There is non-significant association between respondents education and satisfaction with the provision of the facilities.

Suggestions: There is need to create awareness about Thalassemia, Hemophilia and other blood disease because majority of the people are unaware of the them. There is need to aware the people about the adverse effects of cousin marriage which are very common in our social scenario. Blood examination center which are integral part of hospitals, should be made effective in curing such blood disease.

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