Psychosocial and Psychometric Study of Children with Beta Thalassemia Major and their Families

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Abstract

A case control design conducted at Pediatric Hematology Oncology Unit, Zagazig University Hospital on one hundred children with beta-Thalassemia major and another 100 normal children as controls. Their ages ranged from 9-16; both sexes were included in this study to evaluate the effect of this disease on the psychosocial behavior of patients and their parents. This study revealed that the parents' illiteracy, low family income and positive consanguinity had an important role for the children to be chronically ill. They had good personal adjustment as normals in some items as the child feeling of value (self esteem), child feeling of freedom, freedom of individuality and abnormal deviation than controls. Also the social adjustment for these patients showed significant deviation compared to the control in all items of the test except in social levels. All patients showed a significantly lower attention and intelligence score when compared with the control group. Anxiety, Depression and withdrawal for the mothers of the patients showed significantly higher level than the controls. This current study concluded that the psychosocial supportive care is necessary to manage these patients.

Introduction

Beta-Thalassemia, known as Cooley's anemia or Mediterranean anemia, is a chronic, genetically determined hematological disorder, characterized by severe hemolytic anemia and life long dependency on blood transfusions.

This disease predominantly affects inhabitants of the Mediterranean area (Woo et al., 1985).

The chronic disease affects about 10% of the school-age population. In all cases, especially Beta Thalassemia, there is no currently available cure (Eiser, 1992).

Epidemiological surveys show that chronically ill children and adolescents are at greater risk than their healthy peers of developing major psycho-social problems (Mattsson, 1972).

Information regarding the impact of chronic illness on family resources, finances, and relationships is also scarce (Goldberg, et al., 1990).

Aim of the Study

This work was designed to evaluate the effect of the disease, prolonged therapy and follow up on the behavior of patients affected by Beta-Thalassaemia major as well as their families,

Subjects and Method

1. A case control design involved the chart review of 100 consecutive patients with beta Thalassemia (as confirmed by Hb electrophoresis and blood picture attended the Hematology and Oncology Unit of Pediatric Department of Zagazig University Hospital during the period from June 1995 to June 1996. They received regular blood transfusion to keep the Hb level above 6 gm/dl, and treatment in the form of folic acid tablets and parentral desferal S.C. and I.V. Their ages ranged from 9 to 16 years. (Group 1).

2. One hundred healthy children , not suffering of haemolytic anaemia selected from school children, children of some workers in the hospital and healthy rela-

tives of the patients, were matched with the sample in age, sex and socioeconomic standards (Group 2).

3. Mothers of the children in group one (Group 3).

4. Mothers of healthy children considered as a control group for the mother's patients (Group 4).

Methods :

The medical records of the sample group were reviewed as full Medical history including onset, course and duration of illness; frequency of blood transfusion, frequency and types of laboratory test; history of hospitalization and splenectomy and any complications due to disease state or treatment; family history of similar conditions; consanguinity; complete clinical examination arid anthropometric measurements. The land marks and techniques used for measurements of weight and height were recommended by Jelliffe (1966).

Laboratory investigations included complete blood picture and detection of Hb F (fetal hemoglobin).

All cases, controls and their mothers were interviewed by **a** semistructured psychiatric interview based on DSM-IV diagnostic criteria (DSM-1V, 1994).

Psychometric assessment of children:

1. Personality (Attia, 1965): The test is a self-rating instrument for measuring personal and social adjustment of the child. The test is divided into 2 parts, the first part is the personal adjustment which is divided into 6 groups A,B,C,D,E & F. The second part is the social adjustment part, which is divided into 6 groups A,B,C,D,E and F. Each group presented in the form of 8 statements written in colloquial Arabic.

2. Attention (Bonnie, 1991).

3. Intelligence (Zaki, 1978).

4. Socio-economic standards which was graded according to El-Sherbini and Fahmey (1983).

5. Family function was measured with the 12 items general functioning scale of the family assessment device (Byles et al., 1988).

6. Anxiety depression withdrawal scale (Shaheen and Rakhawy, 1972). This scale is used for the assessment of three main symptoms: depression, anxiety and withdrawal and the total summation of the scores of the three items is the assessment of maladjustment.

Statistical analysis:

Data were coded and entered to an Epi info file using Epi version 6.2 software computer package (WHO, 1994). Data were checked for normality measures of central tendency and variability were computed for all variables bivariate analysis "chi-square test" and t-test.

Results

Our sample comprised 61males and 39 females. Their ages ranged between 9 and 16 years with a mean of 11.4+1.5. 25%of cases have one sibling affected by thalassemia and 10% have more than one sibling affected.

35%of cases have a positive parental consanguinity comparing to 20% among controls. 36% of our cases had normal growth, 32% had moderate growth retardation and 32% had severe growth retardation. 51% of cases had adjustment disorder with depressed mood ($X2=4.27$ $p<0.001$) and 42% had adjustment disorder with anxiety disorder ($X2 = 7.52$ $p < 0.01$)

Discussion

Children are the most precious part of a nation's life and the biggest promise for the future. Their survival, development

Table (1)
Socio-demographic characteristics of the studied subjects.

Socio-demographic characters	Patient		Control		X^2	P
	No.	%	No.	%		
Mother's education						
Illiterate	58	58%	39	39%	7.23	<0.01
Educated	42	42%	61	61%		N.S
Father's education						
Illiterate	40	40%	20	20%	9.52	<0.01
Educated	60	60%	80	80%		**N.S**
Mother's occupation						
Empolyed	20	20%	30	30%	2.67	>0.05
Other Occupation	80	80%	70	70%		**N.S.**
Father's occupation						
Fanner	40	40%	25	25%	5.13	<0.01
Other occupations	60	60%	75	75%		**N.S**
Income of family						
< 30 pounds/person	75	75%	60	60%	5.13	<0.05
> 30 pounds/person	25	25%	40	40%		***Sig.***
Crowding index (person/room)	36	36%	56	56%	*8.05*	<0.01
< 2	***64***	***64%***	44	44%		**N.S**
> 2						
Social class						
High	10	10%	12	12%	5.93	>0.05
Middle	34	34%	49	49%		**N.S.**
Low	56	56%	39	39%		

M.S.= Moderate significance N.S.= Not significant.

Table (2)
The statistical analysis of the mean and standard deviation of individual adjustment of patients with beta-thalassaemia major and controls.

Items	Groups	X	±SD	t	P
A **Independence**	Patients Control	4.360 6.960	k1.150 k0.665	19.562	<0.001 H.S
B **Self-esteem**	Patients Control	5.920 5.880	f0.631 ±0.518	0.49	>0.05 **N.S**
C **Child's sense of freedom**	Patients Control	5.050 5.040	k0.609 k0.602	0.116	>0.05 N.S.
D **Child's sense of belonging**	Patients Control	6.700 4.370	k0.655 k1.140	19.498	<0.001 H.S
E **Freedom / individuality**	Patients Control	3.180 3.180	±0.783 k0.796	0.66	>0.05 N.S
F **Free of neurotic disorders**	Patients Control	2.770 2.560	k0.617 ±0.556	2.527	<0.05 Sig.
Total	Patients Control	25.030 30.000	1.845 1.537	20.696	>0.001 H.S

H.S= Highly significant N.S= Not significant

Table (3)
The statistical analysis of the mean and standard deviation of social adjustment of patients with beta-thalassaemia major and controls.

Items	Groups	X	±SD	t	P
A Social levels	Patients	5.080	0.631	0.429	<0.05
	Control	5.120	0.686		**N.S**
B Social skills	Patients	3.900	0.577	24.97	<0.01
	Control	5.890	0.549		H.S
C Freedom Antisocial Inclination	Patients	6.430	0.624	2.077	<0.05
	Control	6.610	0.601		**Sig.**
D Relations in the family	Patients	6.280	0.637	2.639	<0.05
	Control	6.510	0.595		Sig.
E Child's relations at school	Patients	3.160	0.615	39.25	<0.01
	Control	6.470	0.577		**H.S**
F Child's relation in local environment	Patients	3.390	0.584	29.16	<0.01
	Control	6.190	0.761		H.S
Total	Patients	28.280	1.913	33.42	<0.01
	Control	36.750	1.629		**H.S**

N.S=Not sigificant H.S= Highly significant

Table (4)
Distribution of children according to attention.

Items	Patient		Control		χ^2	P
		%	No.	%		
Attention score						
- Low degree of attention at school	63	63%	47	47%	5.17	<0.05 Sig.
- Normal degree	37	37%	53	53%		

Items & Groups	x	±SD	t	P
Attention score:				
Patient Gr.1	33.860	k14.225	8.184	<0.001 H.S
Control Gr.2	56.260	k23.380		

H.S= Highly significant

Groups	Range	X	±SD	t	P
Patient	80-115	96.96	±4.3	16.517	<0.001 H.S
Control	105-120	112.4			

H.S= Highly significant

Table (6)
General functioning scale among families of the children.

Items	Gr.3		Gr.4		X^2	P
	No.	%	No.	%		
1- Problem solving	62	62	71	71	1.82	NS
2- Communication	72	72	76	76	0.42	NS
3- Roles	55	55	65	65	2.08	NS
4- Affective responsiveness	71	71	66	66	0.58	NS
5- Affective involvement	65	65	68	68	0.20	NS
6- Behaviour control	45	45	65	65	2.00	NS
Normal function						
Dysfunction	73	73	76	76	0.24	NS
Normal function	27	27	24	24		
Dysfunction						

N.S=Not significant

Table (7)
Mean (X) and standard deviation (±SD) of (ADWS) of patients' mothers and their control.

Items	Groups	X	±SD	t	
Dperession (D)	Gr. 3	25.200	2.089	44.327	
	Gr. 4	12.680	1.901		
Anxiety (A)	Gr. 3	21.280	1.207	53.702	
	Gr. 4	10.240	1.664		
Withdrawal (W)	Gr. 3	15.840	1.419	51.680	
	Gr. 4	7.280	0.854		
Total	Gr. 3	62.320	2.582		<0.001
	Gr. 4	30.200	2.543	88.646	

ADWS = Anxiety depression withdrwal scale
D = depression **W**=Withdrawal **A**= Anxiety **V**= Versus

and protection are the basic responsibility of the family, community and government (Unicef, 1988). Positive consanguinity between parents was positive in 35% of patients group and 20% of control and this result is nearly similar to that of Der Kaloustian et al. (1980), Vazken et al. (1987), Petrou et al. (1993) and Ragab, et al. (1994) who recorded that a consanguineous marriage are found in more than 20% of the families with chronically ill children, reaching 40% in certain communities. This explains the increased incidence of beta Thalassaemia in our locality due to increase incidence of relative marriage (El-Safy et al., 1993). A consanguineous marriage was found in 70% of sick children and 13.4% of children with carrier state in Egypt (El-Beshlawy et al., 1993).. This can be explained as many of the chronic health problems have a genetic causation like diabetes, haemolytic anemias and bronchial asthma.

As regards the growth retardation, it was severe in 32% of cases. This result is in agreement with Badr et al. (1993), who concluded that the growth of 36% of cases was severely retarded. Also El-Beshlawy et al. (1993) reported that growth rate was below 3rd percentile in 47.4% in males and 66.6% in females. Wahidiyat (1993) recorded that growth retardation was one of the commonest complications of beta Thalassaemia major. The cause of growth retardation is endocrinal gland involvement by iron overload or due to anemia itself (Manenti, 1989). Growth retardation is mainly detected in children with irregular iron chelation, because good iron chelation improves survival and decreases involvement of endocrinal glands and organs by excess iron either due to hemolysis or due to repeated blood transfusions (Vullo, 1990 and Kattian's, 1993).

Psychiatric Morbidity and Personality Assessment

There was poor personal and social adjustment (in most of their items as well as the total scores). These results are similar to the findings of the study of Badr et al. (1993). Thalassaemia influences individual and family psychological functioning. Parentral reaction to diagnosis affects the parent-child relationship. A child translates parentral reaction into personal attitudes of dependency and lowered self-esteem (Nash, 1990). Also, our results agree with those reported by Battle (1975) who found that the child's responses to chronic physical disease includes; depression, aggression, regression and increasing dependence; Emily et al.,(1992) reported feeling of inferiority, and Neil (1979) reported withdrawal from social contact, which can interfere with a child's academic performance and peer relationships in the school setting (James et al., 1993). This makes children at substantial risk for excess psychosocial morbidity (Gortmarker et al., 1990 and Fukunishi, 1990). It can seriously impair the quality of life of the children (Fondu, et al., 1989).

Another study about psychological problems of thalassaemic subject shows subjective conflicts "fear and uncertainty of future due to illness, feelings of aggression and fault, depressive moods and loneliness, problems of communication, (Gausco, 1987). Other studies proved that there is no direct linkage between physical disease and psychological behavior, but the relationships are multidimensional and complex (Orr et al., 1984; Pless and Nolan, 1991).

The most important consideration is the pre-morbid personality of the sick child. Qualities such as temperament, relationship with parents, relatives and friends,

emotional stability, and intellectual abilities all will provide a base from which the child will react to his or her illness (Cartner et al., 1991).

There are indications that certain stages of the illness may be particularly stressful and lead to psychiatric mal-adjustment reactions in children, usually with mood changes. Kovacs et al. (1985) in their study supported our findings as regards the psychiatric morbidity, which revealed that 51% of our cases have chronic adjustment disorder with depressed mood and 42% have chronic adjustment disorder with anxiety disorder. Some studies report a linear correlation between health status measures and psychological adjustment, so that only the most severely affected children have adjustment problems. For example, McNicol et al. (1973) documented increased behavioral problems in only a small group of children with severe and continuing asthma. Comparable findings are available from studies of children with diabetes (Gath et al. 1980) and chronic renal failure (Garralda et al., 1988). The link between severity of illness and psychiatric disturbance seems to apply as much to young preschool children as to older children and adolescents (Daud et al., 1993).

As regards the degree of **attention,** it is apparent from the present study that the thalassaemic patients have a significant low attention compared to the control group. This is in agreement with Prior and Samson (1986) who declared that some chronic illnesses may lead to attention deficit with or without hyperactivity. Also, Constantina et al. (1991) reported that 28% of thalassaemic patients showed severe redcution in their social activity and IQ.

Intelligent quotient (IQ):

Eisenberg (1980) stated that the child's intelligence as measured by intelligence quotient (I.Q) test, is the single variable that correlates most highly with academic success, and poor school performance is commonly explained by poor I.Q. In respect to I.Q. Our work shows that, there is a highly significant decrease in I.Q. in thalassaemic patients than the control group. These results are in agreement with Kury and Rodrigue (1995) who found a child's IQ to be strongly related to the children's illness, duration of medical condition, total hospitalization and higher life-threat medical conditions, all of which interfere with the intelligent quotient (IQ) of the chronically ill child. The effect of anemia is the consequent diminution in the flow of oxygen to brain leading to brain anoxia, which may be added to psychiatric symptoms (Bishry et al., 1977)

The General Functioning Scale of the Family:

The family functioning scale between the thalassaemic patients and control group shows no significant difference between the two studied groups and these results agree with Koura et al. (1994). This indicates that, in our community, the presence of a chronically ill child in the family may be associated with high cohesion and conformity with relieving of the apparent friction in the family. This result is similar to that of Sabbeth (1984) , but disagrees with Cadman et al. (1991). Reiss (1990) and Newackeck and Taylor (1992), have identified the "psychosomatic families" by a family with a chronically ill child, characterized by extreme involvement with one other, extreme responsiveness and sensitivity to each other's moods and needs, a lack of individual autonomy, and little respect for personal privacy. In such families, instead of overt disagreement or conflict, hostility and resentment are submerged. Such repressed hostility may be the cause for all these dysfunctional family interac-

tions. (Stein et al., 1982). Neil (1979) stated that the social context of the family, the psychological status and history of its members have central importance in the way the family interprets the illness and handles the situation. Chronic illness in a child makes it more difficult for both parents to work outside home, thereby diminishing families financial resources and the daily burden of care rests mainly on the families (Steven et al., 1990).

Anxiety, Depression, Withdrawal

The impact of the child's illness on the family can occur in the form of anxiety, depression and withdrawal (Bishry et al., 1977). Our results show that in the three items of the ADWS (Anxiety, Depression, withdrawal) the mothers of Thalassaemia major patients have higher mean scores than the control and the difference is statistically highly significant in all items. These results agree with those of Badr et al. (1993) and Koura et al. (1994), where they reported that the majority of mothers of the chronically ill children were more depressed and anxious than those of healthy ones. In our study, anxiety was noticed in the mothers as they suffer many problems; frequent visits for medical care and laboratory procedures disrupt family life and parents employment; also partial abandonment of the well children especially during admission of the mother to the hospital with her affected child. Perhaps, the problems may also be due to the cost of transport as some parents come from far places and also the cost of buying blood in many instances is an important factor in producing anxiety. Also depression is noticed in most of mothers of thalassaemic patients especially those with more than one affected child. Guilt due to transmission of the disease and death anxiety were not apparent in the mothers, as most of them have no idea about the hereditary nature of the illness and the fact that they had transmitted the illness to the child. Tsiantis et al. (1982) reported that parents of children displayed various patterns of emotions (guilt, death anxiety, denial of feeling) and their behaviour towards the child was inappropriate (over protective, conspiracy of silence). This could affect his or her psychological development and lead to tension within the family. Parental reactions and emotional manifestations can affect the child in several ways. This was similar to the findings of the study of Sabbeth (1984) and Koura et al. (1994). **As** the severity of the child chronic illness increased, the mother's depression and anxiety state became more due to the increase in the physical and mental stress on her (in feeding, cleaning and giving treatment to the diseased child), This is in agreement with the findings of the study of Fisman and Wolf (1991) who found that the presence of a child with a pervasive developmental disorder had a significant effect on maternal mental status resulting in a state of depression.

Conclusion

In the care of the chronically ill child, one aim is to minimize the relationship between physical and emotional conditions because there are a variety of reasons to expect increased psychosocial morbidity among these children.

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دراسة نفس إجتماعية و نفسية للاطفال المصابين بمرض بيتاسالاثيميا الجسيم و عائلاتهم

تم عمل الدراسة بقسم امراض الدم للاطفال بمستشفى الزقازيق الجامعى على مائة مريض بمرض البيتاسالاثيميا، و مائة اخرين ممن لا يعانون من هذا المرض تتراوح اعمارهم بين تسع وستة عشر سنة من كلا الجنسين.

الهدف من البحث هو معرفة تأثير المرض على الحالة النفس اجتماعية لهؤلاء الاطفال.

وقد اظهرت الدراسة أن عدة عوامل مثل امية الاباء و قلة دخل الاسرة ووجود قرابة من الدرجة الاولى قد تؤثر على جعل المرضى مزمنين.

كذلك وجد خلل فى الاتزان الاجتماعى لهؤلاء الاطفال مقارنة بالعينة الضابطة، ايضا ظهر انخفاض فى مستوى الذكاء وفى التركيز مقارنة بالعينة الضابطة و من ثم فقد وجد ان هؤلاء الاطفال محتاجون لعناية نفسية و اجتماعية اكثر من الاطفال العاديين.