

# Maternal - Child Relationship and Psychosocial Development of Thalassaemic Children

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This study was carried out to detect the emotional status of mothers of thalassaemic children, as well as the maternal- children relationship and their effects on the psychosocial development of the children. The study includes fifty children with B- thalassaemia major, their ages ranged from three to nine years and duration of illness ranged from one to eight years with their mothers attending Hematology and Oncology Unit of Pediatrics Department , Zagazig University Hospital. Fifty five healthy school children of the same ages and their mothers were chosen as controls. All mothers of the patients and controls were subjected to Middle sex Hospital Questionnaire. Normal and diseased children were subjected to full history general medical examination, including assessment of physical development and full laboratory investigations.

Psychometric assessment of healthy and patient groups included parental acceptance- rejection scale and Boyed developmental scale for assessment of psychosocial development. Our results showed that the mothers of thalassaemic children had a higher scores of anxiety (10%), phobia (10%), obsession (38%) hypochondrisis (18%) and depression (24%), than mothers of normal children who presented with anxiety (0%), phobia (9%), obsession (3%), hypochondrisis (11%) and depression (15%). The mean of the acceptance (Warmness) of the mothers toward healthy children was greater than the acceptance of mothers toward patients with significant difference.

It was reported that whereas depressive symptoms became manifested, the mother warmnes toward their children decreased. We noticed that as the symptoms of psychiatric illness became manifested of the mothers, their degree of rejection toward their children increased, but without significant difference except for anxious mothers and their diseased children and anxious and depressed mothers and their healthy children showed significant difference. As regard physical development of patients, 50 % were of normal height and weight, 34% suffered from stunted growth and 16% with stunted and wasted growth. As regard psychosocial development, 60% were well and 40% were less psychosocially developed and there was positive relation between acceptance of mothers toward their diseased children and their psychosocial development.

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## Introduction

Beta- thalassaemia major is the commonest haemolytic anaemia in Egypt (Sabbry, 1973).

Children affected by this disease were kept alive by repeated blood trans-

fusion. Transfusion therapy may aim at keeping hemoglobin concentration at reasonable level to maintain as near as possible normal growth and development (Economidou, 1982).

Children with moderate to severe handicapping long term illness are at risk, not only medically, but for complex social, educational and emotional difficulties (Perrin and Gerrity, 1984).

Mothers of chronically ill children experience anger and bitterness. Many have noted the prevalence of depression among them.

Different families will react differently to having a child with a chronic disease. Some will be destroyed, others will be adjusted at great cost (Battle, 1975). Still others are able to cope with the initial prognosis of their child's illness, their acceptance gradually subsides to a chronic state of apprehension mixed with hope that the child will be cured (Marten and Mauer, 1982).

#### **This study aimed to:**

Detect the effect of chronic illness and prolonged therapy (of thalassemic children) on their mothers and its effect on maternal- child relationship.

Maternal acceptance and/ or rejection of their children and its effect on their psychosocial development.

#### **Subjects and Methods**

This work was carried out on Haematology and Oncology Unit of Pediatric Department of Zagazig University Hospital, during the period from 1994 to 1995.

This study was carried out on 50 patients with Beta thalassaemia major and their mothers and 55 subjects as control for the patients and their mothers.

#### **Subjects (Samples):**

**Group I<sub>A</sub>:** 50 patients with Beta thalassaemia major. Their ages ranged from

3 to 9 years, 32 were males and 18 were females and duration of illness ranged from 1 to 8 years. These patients attending to the Pediatric department (Haematology) and Oncology Unit of Zagazig University) for regular transfusions to keep the Hb level above 6gm/dL. Treatment is offered as free charge in the form of folic acid tablets and parenteral desferal (s.c. & i.v.).

**Group I<sub>B</sub>:** Mothers of the same patients attending to the Pediatric Department, Haematology and Oncology Unit of Zagazig University with their kids.

**Control Group:** 55 healthy children not complaining of haemolytic anaemia selected from school children and children of some workers in the hospital of the same age of the patients and their mothers as controls.

#### **Methods**

All patients and controls were subjected to the following:

a- Full medical history: including onset, course and duration of illness; frequency of blood transfusion; frequency and types of laboratory tests, history of hospitalization and splenectomy and any complications due to disease state of treatment.

General medical examination and development (weight, height, head circumference) and results were compared with WHO percentile charts for development.

Facies, clinical jaundice, skin discoloration, leg ulcers or pigmentation and colour of urine and stool.

Local examination of chest, heart and abdomen (liver, spleen and lymph nodes).

b-Laboratory investigations:

- Complete blood picture.

- Detection of HB F by alkaline denaturation at first to be confirmed in suspected cases by haemoglobin electro-

phoresis using cellulose acetate strips (Marengo Rowe Method, 1965).

c- Psychometric assessment:

- All mothers of the patients and their controls were subjected to : Middle sex hospital questionnaire (M.H.Q.) (Gawad et al., 1972). This questionnaire measures the symptomatology of the following disease: anxiety, phobia, obsession, somatic scale, depression and hysteria.

All the patients and their controls were subjected to:

a- Parental acceptance-rejection scale:

The used scale is the arabic version of parental acceptance/ rejection scale of Roland-P. Rhoner 1984, 1986, and represent parental behaviour toward their children. This scale is formed of four subscales; warmth, aggression, neglectance and rejection.

Warmth subscale represent acceptance and the others subscales represent

rejection.

All the questions were answered by the child himself, while younger children (age below 5 years, their mothers answers about their behaviour toward their children) (Salama, 1986).

b- Boyed developmental scale (Boyd, 1974):

For psychosocial assessment, according to this scale, the child was considered well psychosocially developed if his score of expected psychosocial milestones for his age was 50% or more and less psychosocially developed if he scored less than 50% of the expected items for his age.

Statistical analysis (Armitage, 1971):

Mean (X), standard deviation ( $\pm$ S.D.) (F) test and (t) test were used.

## Results

Table 1  
Emotional States of The Mother's of Thalassaemic Children and Thier Controls

| Items of M.S.Q. | Mothers' of Thalassaemic Children |    |                  |    |            |    | Mothers' of normal Children |    |                  |    |            |    |
|-----------------|-----------------------------------|----|------------------|----|------------|----|-----------------------------|----|------------------|----|------------|----|
|                 | No disease                        |    | Subclinically D. |    | Manifested |    | No disease                  |    | Subclinically D. |    | Manifested |    |
|                 | No.                               | %  | No.              | %  | No.        | %  | No.                         | %  | No.              | %  | No.        | %  |
| Anxiety         | 25                                | 50 | 20               | 40 | 5          | 10 | 39                          | 71 | 16               | 29 | -          | -  |
| Phobia          | 12                                | 24 | 33               | 66 | 5          | 10 | 18                          | 33 | 32               | 58 | 5          | 9  |
| Obsession       | 4                                 | 8  | 27               | 54 | 19         | 38 | 16                          | 29 | 37               | 67 | 2          | 3  |
| Somatic anxiety | 19                                | 38 | 22               | 44 | 9          | 18 | 24                          | 44 | 25               | 45 | 6          | 11 |
| Depression      | 9                                 | 18 | 29               | 58 | 12         | 24 | 30                          | 55 | 17               | 31 | 8          | 15 |
| Hysteria        | 38                                | 76 | 11               | 33 | 1          | 2  | 40                          | 73 | 10               | 18 | 5          | 9  |

This table shows that; manifested diseases of middle sex questionnaire among mothers of thalassaemic children represented as anxiety 10%, phobia 10%, obsession 38%, somatic symptoms 18% and depression 24%, which are greater than manifested diseases among mothers of normal children which represented as anxiety 0% phobia 9%, obsession 3%, hypochondria 11% and depression 15%.

**Table 2**  
Maternal / Child Relationship of Thalassaemic and Normal Children.

|                     | Thalassaemic children<br>Mean $\pm$ S.D. | Normal Children<br>Mean $\pm$ S.D. | t       | P         |
|---------------------|------------------------------------------|------------------------------------|---------|-----------|
| Acceptance (Warmth) | 65.26 $\pm$ 9.14                         | 73.20 $\pm$ 8.54                   | 4.6037  | 0.000075* |
| Rejection           | 72.78 $\pm$ 13.57                        | 72.35 $\pm$ 15.57                  | 0.15198 | 0.874127  |

This table shows that there is a significant difference between warmth of mothers toward their thalassaemic children and mothers toward their normal children.

**Table 3 a**  
Emotional States of Mothers and Acceptance (Warmness) of Thalassaemic Children and Their Control Children

| Emotional States | Mothers' of Thalassaemic Children |                                          |                                       |        |          | Mothers' of normal Children |                                          |                                       |        |           |
|------------------|-----------------------------------|------------------------------------------|---------------------------------------|--------|----------|-----------------------------|------------------------------------------|---------------------------------------|--------|-----------|
|                  | No disease<br>X $\pm$ S.D.        | Subclinically<br>disease<br>X $\pm$ S.D. | Manifested<br>disease<br>X $\pm$ S.D. | F      | P        | No disease<br>X $\pm$ S.D.  | Subclinically<br>disease<br>X $\pm$ S.D. | Manifested<br>disease<br>X $\pm$ S.D. | F      | P         |
| Anxiety          | 65.76 $\pm$ 9.44                  | 66.35 $\pm$ 9.44                         | 58.4 $\pm$ 6.6                        | 1.63   | 0.205179 | 74.39 $\pm$ 9.59            | 70.31 $\pm$ 4.13                         | ---                                   | 1.63   | 0.1049    |
| Phobia           | 67.25 $\pm$ 7.46                  | 64.46 $\pm$ 9.80                         | 65.8 $\pm$ 9.18                       | 0.412  | 0.670518 | 77.31 $\pm$ 10.05           | 70.833 $\pm$ 6.86                        | 71 $\pm$ 5.477                        | 4.033  | 0.0729    |
| Obsession        | 65.75 $\pm$ 5.85                  | 64.74 $\pm$ 10.09                        | 66.63 $\pm$ 8.19                      | 0.5814 | 0.5814   | 74.75 $\pm$ 9.23            | 73.08 $\pm$ 3.92                         | 71.9 $\pm$ 6.02                       | 0.582  | 0.5270    |
| Somatic anxiety  | 63.21 $\pm$ 9.91                  | 65.73 $\pm$ 8.44                         | 68.44 $\pm$ 9.02                      | 1.056  | 0.357051 | 75.39 $\pm$ 9.30            | 73.21 $\pm$ 4.36                         | 70 $\pm$ 15.07                        | 2.6240 | 0.0637    |
| Depression       | 65.73 $\pm$ 10.67                 | 64.93 $\pm$ 8.58                         | 65.67 $\pm$ 9.27                      | 0.043  | 0.957989 | 75.53 $\pm$ 7.49            | 70.59 $\pm$ 4.39                         | 61.80 $\pm$ 11.82                     | 6.366  | 0.040011* |
| Hysteria         | 66.11 $\pm$ 8.64                  | 61.92 $\pm$ 10.3                         | 74 $\pm$ 0.0                          | 1.447  | 0.244527 | 73.03 $\pm$ 8.75            | 75.1 $\pm$ 8.98                          | 70.4 $\pm$ 6.148                      | 0.512  | 0.608072  |

This table shows that there were no significant differences between emotional states of mothers and warmth of their thalassaemic children while there was only differences between depressed mothers and warmth of their normal children.

**Table 3 b**  
Emotional States of Mothers and Rejection of Thalassaemic Children and Their Control Children

| Emotional States | Mothers' of Thalassaemic Children |                                          |                                       |        |           | Mothers' of normal Children |                                          |                                       |       |          |
|------------------|-----------------------------------|------------------------------------------|---------------------------------------|--------|-----------|-----------------------------|------------------------------------------|---------------------------------------|-------|----------|
|                  | No disease<br>X $\pm$ S.D.        | Subclinically<br>disease<br>X $\pm$ S.D. | Manifested<br>disease<br>X $\pm$ S.D. | F      | P         | No disease<br>X $\pm$ S.D.  | Subclinically<br>disease<br>X $\pm$ S.D. | Manifested<br>disease<br>X $\pm$ S.D. | F     | P        |
| Anxiety          | 74.28 $\pm$ 13.95                 | 68.35 $\pm$ 12.82                        | 83.0 $\pm$ 8.09                       | 2.83   | 0.047264* | 68.54 $\pm$ 4.54            | 81.63 $\pm$ 14.20                        | ---                                   | 9.290 | 0.00386* |
| Phobia           | 75.33 $\pm$ 10.08                 | 73.03 $\pm$ 14.01                        | 65 $\pm$ 7.64                         | 1.041  | 0.362221  | 68.45 $\pm$ 5.32            | 75.73 $\pm$ 15.8                         | 67.60 $\pm$ 11.91                     | 1.612 | 0.208    |
| Obsession        | 71.18 $\pm$ 13.45                 | 73.28 $\pm$ 13.85                        | 72.63 $\pm$ 3.8                       | 0.0839 | 0.3792    | 71.95 $\pm$ 3.98            | 77.59 $\pm$ 12.10                        | 79.82 $\pm$ 17.39                     | 1.67  | 0.1248   |
| Somatic anxiety  | 72.63 $\pm$ 13.18                 | 70.82 $\pm$ 14.35                        | 77.89 $\pm$ 12.54                     | 0.864  | 0.568786  | 70.81 $\pm$ 1.02            | 70.96 $\pm$ 18.33                        | 87 $\pm$ 16.43                        | 2.59  | 0.082    |
| Depression       | 73.8 $\pm$ 12.45                  | 71.28 $\pm$ 14.47                        | 77.5 $\pm$ 12.49                      | 0.573  | 0.024397  | 67.13 $\pm$ 2.56            | 79.06 $\pm$ 18.45                        | 77.63 $\pm$ 13.11                     | 4.18  | 0.0202*  |
| Hysteria         | 72.97 $\pm$ 14.39                 | 71.83 $\pm$ 11.82                        | 77.0 $\pm$ 0.0                        | 0.078  | 0.924397  | 71.63 $\pm$ 4.24            | 76.30 $\pm$ 20.38                        | 70.2 $\pm$ 17.18                      | 0.406 | 0.6741   |

In thalassaemic children, there was only significant difference among anxious mothers and their children. In healthy children, there were significant differences among anxious and depressed mothers and their children.

**Table 4**  
Physical Development Among Thalassaemic Patients

|                | Patients with normal weight and height |     | Patients with stunted growth |     | Wasted patients |     | Stunted and wasted patients |     |
|----------------|----------------------------------------|-----|------------------------------|-----|-----------------|-----|-----------------------------|-----|
|                | No.                                    | No. | No.                          | No. | No.             | No. | No.                         | No. |
| <b>Males</b>   | 16                                     | 32  | 11                           | 22  | -               | -   | 5                           | 10  |
| <b>Females</b> | 9                                      | 18  | 6                            | 12  | -               | -   | 3                           | 6   |
| <b>Total</b>   | 25                                     | 50  | 17                           | 34  | -               | -   | 8                           | 16  |

This table shows that 50% of thalassaemic children were of normal height and weight, 34% stunted growth and 16% stunted and wasted.

**Table 5**  
Psychosocial Development Among Thalassaemic Children and Their Control

|                       | Thalassaemic Children<br>Mean $\pm$ S.D. |    | Normal Children<br>Mean $\pm$ S.D. |    |
|-----------------------|------------------------------------------|----|------------------------------------|----|
|                       | No.                                      | %  | No.                                | %  |
| <b>Well Developed</b> | 30                                       | 60 | 52                                 | 95 |
| <b>Less Developed</b> | 20                                       | 40 | 3                                  | 5  |

This table shows that 60% of thalassaemic children and 95% of normal children were psychosocially well developed. While 40% of thalassaemic children and 5% of normal children were less psychosocially developed.

**Table 6**  
Maternal / Child Relationship and Psychosocial Development Among Thalassaemic Patients

|                       | Well Developed<br>Mean $\pm$ S.D.     | Less Developed<br>Mean $\pm$ S.D.   | t                    | P                   |
|-----------------------|---------------------------------------|-------------------------------------|----------------------|---------------------|
| Warmness<br>Rejection | 68.10 $\pm$ 7.96<br>73.33 $\pm$ 10.34 | 61 $\pm$ 9.313<br>71.95 $\pm$ 17.45 | 2.886602<br>0.349927 | 0.005927*<br>072794 |

It is noticed that, there is a significant difference between warmness of mothers and well and less psychosocially development of thalassaemic children.

## Discussion

In spite of a large amount of information pointing to a retardation in physical growth in patients with Beta thalassaemia major, but very little has been said concerning maternal- child relationship and psychosocial development of thalassaemic children.

In early studies, (Bishry, 1977) found that anxiety and depression are more common among mothers of thalassaemic children. And (Tsiantis et al. 1982) studied family reactions in parent group with Beta-thalassaemic children. Results have shown that parents displayed various patterns of emotions, guilt accompanied by depressive feelings. It was strong and associated with self blame due to the fact that the parents had transmitted the illness to the child. Anxiety about death was common and was linked with life expectancy of the child. Denial of the problem and feelings, some parents were ashamed and tried to deny that there was anything wrong with the child.

In our study, mothers of patients showed higher scores on obsession, depression, somatic symptoms, anxiety and phobia than mothers of normal children, this can be explained by an over stress on mothers of patients through frequent visits for medical care and laboratory procedures, frequent admission of the mother to the hospital with her affected child which disrupt their employment and the cost of treatment.

Overprotection and the level of daily care the child requires and fear of complications, this may be responsible for high scores of obsession in already susceptible mothers.

As regard maternal- child relationship, we noticed that thalassaemic children had significantly lower acceptance (warmth) than healthy children, this can be explained as, a child frequently trans-

lates parental reactions into personal attitudes of dependency and lowered self-esteem (Nash, 1990) and also limitation imposed by parents may be interpreted by the child as a type of rejection and his pessimistic outlook on life.

Concerning the emotional states of mothers and the acceptance and rejection to their children (Tables 3a,b) we noticed that rejection to children increases as emotional states of mothers became a manifested disease.

We found that there was a significant difference between depressed mothers and acceptance to their healthy children while as regard rejection significant difference between anxious and depressed mothers and rejection of healthy children, while this noticed only for anxious mothers and their diseased children. This may be explained as depressed mothers can not take care of themselves and others and anxious mothers become irritable and intolerable to any duty or stress, consequently these reactions will be interpreted by children and others as a form of rejection. Growth disturbances are a major clinical feature of patients with untreated thalassaemia major. While women patients show normal growth and development, many suffer from growth retardation and failure of puberty (Christos, 1993).

El-Safy's study (1993) found that growth retardation was detected in 33% of thalassaemic patients especially those above 7 years old (in a sample of 300 patients).

Our study revealed that 50% of patients had growth retardation (34% with stunted growth and 16% with stunted and wasted growth). This may be due to small random sample of the patients studied.

As regard psychosocial development, 5% of healthy children and 40% of thal-

assaemic children were less psychosocially developed, this result may be explained through; a chronic illness demands acceptance of an altered body image and prolonged dependence on skills and support of others (Perrin and Gerrity, 1984). Attainment of optimal development may be promoted or hindered. As the child's environment widens, negative attitudes may be reinforced. Physical differences that lead to teasing and limitation imposed by others may be interpreted by the child as personal inadequacy. Such feelings often persist through adolescence due to the individual's lag in physical growth, marginal academic record and poor self concept (Nash, 1990). In addition of the above; mothers worry for the sick child lead to surplus parental guardianship, so child chance for independent life diminishes.

An interesting finding in this study was a significant relationship between well and less psychosocial development in relation to the acceptance of the mothers. This can be attributed to the mother's acceptance, patients self-esteem and their pessimistic outlook on life will be improved. (Midence et al. 1994) reported that the psychosocial adaptation of children and adolescents with chronic illness has been associated with the family attitudes and behaviour and social and environmental support.

In conclusion, the above data, verified the necessity of psychiatric assessment for the patients and their families to get over the psychosocial consequences of their disease.

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### **Le rapport enfant - maternel et le développement psychosocial chez les enfants avec Thalassaemie**

**Cette étude était de découvrir la condition émotive des mères qui ont des enfants souffrants de thalassaemie, le rapport enfant maternel, et leur impact sur le developpement psychosocial de ces enfants.**

**On a étudié 50 enfants avec B- thalassaemie majeure (l'âge: 3-9 ans). La durée de maladie était 1-8 ans . Les malades et leurs mères vont à l'hôpital universitaire de Zagazig, le département d'oncologie et hematologie. Toutes les mères et le groupe de contrôle ont fini le questionnaire de Middle sex. L'évaluation des enfants malades et normals a compris un examen clinique et laboratoire.**

**L'évaluation psychometrique a compris l'échelle d'acceptation- rejet de parents et l'échelle Boyed de développement.**

**Les resultats ont démontré que les mères des enfants malades (groupe 1) ont plus d'anxiété (10%), de la phobie (10%), de l'obsession (38%), de l'hypochondrie (18%) et de la dépression (24%) que les mères du groupe de controle (group 2), le niveau de l'acceptation est plus haut chez les mères group 2 que chez le groupe 1.**

**La psychopathologie était associée significativement avec le rejet.**

**Le developpement physique était normal chez 50% de malades, cependant que 34% ont souffert du délai de developpement et 16% de la consommation et délai. 40% avait un délai de developpement psychologique.**

**L'acceptation des mères était associée avec le developpement psychosocial.**

## علاقة الطفل بأمه والنمو النفسى الاجتماعى

### في الأطفال المصابين بالثلاسيميا

إستهدفت هذه الدراسة إستعراض الحالة النفسية العاطفية للام بطفلها المصاب بالثلاسيميا الجسيمة وعلى تأثير المرض على النمو النفسى الاجتماعى والعلاقة بين الطفل وأمه، وقد اشتمل البحث على خمسين طفلاً تتراوح أعمارهم بين الثالثة والتاسعة بالإضافة إلى عينة ضابطة قوامها خمسة وخمسين طفلاً سليماً. وقد طبقت بعض المقاييس النفسية على الأم واستخدم مقياس بويد للنمو العصبى النفسى بالإضافة إلى الفحوصات المعملية والجسمانية الأخرى. وقد أظهرت النتائج ارتفاع معدلات أعراض القلق والإكتئاب والمخاوف والوساوس فى أمهات هؤلاء الأطفال بالإضافة إلى اضطراب علاقة الأم بالطفل بدرجة تتناسب طردياً مع إرتفاع معدل الأعراض بالإضافة إلى اضطراب النمو الجسمانى والعصبى فى هؤلاء الأطفال، وتناقش الدراسة النتائج وتستخلص التوصيات.