

## **PSYCHOSOCIAL ASPECTS OF THALASSEMIA**

Evgenia T. Georganda, Psy.D.  
Ioannina, Greece, October 1994

When discussing the psychosocial aspects of thalassemia we refer to three levels of functioning:

- A. The level of the individual,
- B. The level of the family system and
- C. The level of the social cultural system.

The presence of a disorder affects all three levels to varying degrees and in different ways. All three levels of functioning are inter-related and what happens to the one level influences the others. Although, most of the emphasis should be on the well being of the affected individual all three levels need to be addressed in order to achieve maximum results.

### **A. The INDIVIDUAL**

When referring to the individual level of functioning we have two goals: First and foremost is to ensure that the individual receives the proper medical treatment so that s/he survives and second, that, once survival has been attained, the individual achieves the best possible adjustment to the disorder. As far as the first goal is concerned tremendous progress has been achieved in the medical field, making it possible for individuals with thalassemia and other genetic blood disorders to survive well beyond childhood and adolescence.

Thalassemia International Federation has now in its possession a treatment protocol that has been written in collaboration with medical experts in the field which, if followed, will ensure that individuals with thalassemia will survive and will face as few medical complications as possible. Unfortunately this treatment protocol is not yet followed by all countries that have thalassemia patients. The reasons are many. The two most important ones are:

- lack of knowledge and information and
- lack of necessary financial resources in order for the full treatment to be provided. In this respect social policies and provisions made by governments are of tremendous importance and will be discussed under sociocultural level of functioning.

Beyond survival, however, we have a second goal which is referred to as: "best possible adjustment of the individual to the disorder". In psychological terms adjustment is the ability of the individual to fit into given circumstances (for example the ability of the individual to adjust to the overnight iron chelation treatment, lack of which would imply non-compliance to the treatment and possibly death) as well as his/her ability to change the circumstances to meet his/her needs (which for example, can be seen in the effort of thalassemic patients to improve the conditions of their blood transfusions). In other words adjustment is both a passive as well as an active process and is a function of both:

- the SITUATION with which the individual is confronted with and
- the PERSONALITY of the specific individual.

The situation a thalassemic is confronted with is a difficult and demanding one. S/he has to deal with a chronic illness that requires painful medical procedures and a lot of extra

care and attention. Thus, the task of adjusting to its presence is a difficult and complicated one that makes tremendous demands on his/her personal resources. In this respect social policies could once more play a very important role by simplifying the necessary bureaucratic procedures that are often required, for example, for providing with the necessary desferal or the necessary check-ups.

The personality of the individual is of course a very unique aspect of the equation that will greatly influence the outcome of the individual's struggle to adjust. It is a well known fact that the personality of each one of us is greatly influenced by the environment in which s/he grows up. When we refer to environment we are including both the specific family in which the individual is born and the specific society in which the family functions.

## B. THE FAMILY

Research has shown that the DIAGNOSIS of a chronic hereditary disease like thalassemia is a devastating, heartbreaking and earthshaking experience for the parents (Bruhn 1977, Collins Moore, 1984, Friedlch 1977, Georganda, 1988). It is also well known that the first six-seven years of a child's life are crucial for the development of his/her personality. One of the most critical elements for the development of adequate ego strength and adequate resources for dealing with life's demands is the MOTHER-CHILD BOND that is established in the first year of life. Usually, the diagnosis of thalassemia occurs within this first year. Most often parents react to the diagnosis with intense grief and disappointment, feeling guilty, depressed, sad and angry. All these intense emotional reactions cannot but influence the mother-child bond leading to an early trauma in the child's personality development.

The first step of intervention, for ameliorating or preventing such an obstacle in the child's development and later adjustment to the disorder, is the establishment of psychological services that will help parents deal with their intense grief and the unavoidable negative emotional reactions that they experience at the time of the diagnosis. Psychological services can be in the form of couples' counseling, support groups for parents as well as educational seminars. The diagnosis cannot just be thrown at the parents by physicians without any further attention to the tremendous difficulties that they have to face. Of course parents could ask for such support themselves but it is a well known fact that in most societies there is a negative implication around the issue of seeking for psychological services. Thus, the social and medical systems have a responsibility towards the establishment of such services, taking away the added stigma that such intervention brings forth.

In addition to the above, research has shown that the presence of a chronic hereditary disease brings on more permanent changes in the way the family system functions. It has been observed that the relationship of parents with the ill child changes (Mattson, 1972, Penn, 1983, Velasco de Parra, et. al, 1983, Walker, 1983). Parents may become critical and rejectful or they may become overindulgent and overprotective limiting the child's already restricted functioning. Very often parents become very lax with their discipline allowing the child to have the most important position in the family. The child functions as the center of the family unit often interfering with the mother-father relationship. The family may face further problems because the child is very close to the mother who just takes care of the ill child and neglects her husband and the other children in the family. Siblings may become jealous of the ill child and feeling neglected and left out may develop intense rivalry with their sibling and/or psychological problems so as to finally manage to draw the attention of the parents.

These faulty patterns of functioning and communication within the family may be extended beyond the nuclear family to the relationship of the parents with their relatives

and friends (Georganda, 1988, Tsiantis, et.al. / 1982). Often they are secretive, they feel ashamed of having an ill child and do not discuss it. Feelings, thoughts, worries, fears, anxieties, etc. are not discussed but are kept inside each individual leading to further problems. The ill child is isolated from peers and is hidden from society. Very often, in the not so distant past, children with thalassemia were not allowed to go to school. They were not allowed to play or to be involved in all the normal activities that a young child should be involved in so as to develop an adequate self-image and self-esteem (Blumberg, et.al., 1984, Gardner, 1977, Kellerman, et.al., 1980).

Following the example of the parents, children also become secretive and do not externalize how they feel. They do not talk to friends about the illness fearing that they will be rejected, and are not involved in all the normal activities of their age. As a result they often feel that there is something wrong with them, that they are inferior, inadequate, something less or worse than others. These problems of self-esteem are often compounded by physical differences (when proper medical treatment has not been given from early on) which lead to a poor self-image and to feelings of depression and hopelessness.

If psychological services were to be provided early on, a lot of these faulty patterns of functioning and communication could be prevented. This would ensure a much smoother process of adjustment to the disorder both for the parents as well as for the individual. Unfortunately, such services are not yet part of the routine treatment protocol and we see a great number of families as well as individuals that face problems not due to the illness per se but due to its psychological impact.

In some parts of the world and for other chronic and/or life threatening illnesses, like cancer, a psychologist is part of the treating team. The role of the psychologist is to provide services not only to the families and the patients but to the medical professionals as well. Physicians as well as nursing staff dealing with individuals with chronic illnesses carry a tremendous burden. Resistance to treatment by patients, displaced anger from parents and adult patients who are frustrated with their difficulties, conflicts within the unit, lack of adequate communication between staff and between staff and administration, and/or patients, are only some of the many problems that have to be faced and dealt with.

It is becoming obvious that the presence of a psychologist is not a luxury, or something to be avoided as unnecessary. The issue is not merely the survival of the individual but also his/her ability to function well and to live well. To be a psychologically healthy individual that can be a positive addition to society and not a burden to it. In terms of the actual ability of an individual with thalassemia to be creative, competent and productive there is ample evidence that the disorder itself, the physical shortcomings it creates, are not necessarily a hindrance. What seems to be an obstacle is his/her ability to adjust to the psychological demands of the disorder. For adult patients, who are no longer as dependent on their families, psychological services in the form of support groups and/or individual psychotherapy could be of great value. Such services could help provide the necessary insight and the necessary skills for facing the emotional demands that dealing with a chronic health problem creates.

### C. THE SOCIAL/CULTURAL SYSTEM

Not much attention has been given to the effect that thalassemia has on the social system. The one most obvious and most important way by which this system is affected is the financial aspect. Whether we are talking about prevention or treatment we can see that the cost is extremely high. Of course, as is the case with all disorders, whether physical or mental, prevention is much more cost effective than treatment. In a simple

estimation of the cost of full treatment of thalassemia patients in Greece, for example, we see that it is approximately 3 to 4 million drachmas per year per patient. Of course this figure varies from patient to patient in relation to his/her age and the medical complications that are present. In Greece we have approximately 3.000 patients, which means that the budget just for the care of thalassemics is about 12 billion drachmas per year. As is understandable this is a very significant amount in relation to the total budget that the Ministry of Health Care Services has at its disposal. In some countries, as for example Iran, it is estimated that there are approximately 15.000 patients with thalassemia, which implies approximately 150 million dollars per year just for providing these patients with desferal.

As is obvious from these numbers the financial cost for treating thalassemia in an aspect that cannot be underestimated. The cost of proper medical treatment is so high that only very few fortunate individuals, or families of individuals could cover by themselves. If patients are to survive it is the government of each country that has to provide them with the necessary means. Unfortunately, however, not all countries have the financial resources needed for providing the best to their citizens. Very often, even in countries that could afford it the full treatment is not provided for free creating a tremendous financial burden on the families and the individuals. This is an aspect of thalassemia that is not often talked about. If we were to look, however at thalassemia on a global scale we would see that only a very small number of patients are fortunate enough to not have to worry about their survival and the cost it implies.

As mentioned already, prevention is much more cost effective than treatment. Thus, it is important for governments and policy makers to understand the value of prevention programs. Such programs need to focus on two aspects. The one is the most obvious and the one that is already provided for in most countries. That is, prevention in terms of PREMARITAL COUNSELING and PRENATAL DIAGNOSIS for decreasing or eliminating the birth of new individuals with chronic disorders. The other aspect of prevention is more insidious but yet equally important. It refers to the prevention of maladjustment of individuals and their families to the disorder.

The social system influences significantly the way the family and the individual view the disorder and the way they cope with it. In other words, societies which view chronically ill or handicapped individuals with prejudice are to a large extent responsible for creating added problems to these individuals and their families. When parents are viewed as carrying the "stigma" for thalassemia and patients are viewed as weak, helpless and inferior it is to be expected that they may end up behaving in such a manner. The family feels stigmatized (and actually has been stigmatized by the system) and the individual feels incompetent, incapable and inferior because this is how s/he has been treated by the system (both the family system and the social system).

The social/medical/cultural system have thus an important role to play in terms of preventing the creation of maladjusted individuals by providing with:

- EDUCATIONAL programs that inform the general public regarding the genetic blood disorders prevalent in their area. What these disorders are, how they are transmitted from generation to generation, how they are prevented and treated. This will serve the double purpose of prevention of new cases as well as a decrease in the fear and prejudice that having such a disorder implies to the general public. It may also help insure availability of blood which, in most countries is a serious problem.
- In addition to these educational programs aimed at the general public, it is important that families and individuals with the disorder receive PSYCHOLOGICAL SUPPORT. Such services will help prevent problems in their adjustment to the disorder. Well adjusted individuals are a positive

addition to the work force of a society, contributing to its progress and prosperity. Thus, all three levels of functioning --the individual, the family, and the social systems--will profit as a result of educational programs and psychological services.

## REFERENCES

- Blumberg B., Lewis, J.M., & Susman, E. J. Adolescence: A time of transition. In G. Eisenberg, L.C. Sutkin, & M.A. Jansen (Eds.) *Chronic illness and disability through the life span: Effects on self and family*. New York: Springer, 1984.
- Bruhn, J.G. Effects of chronic illness on the family. *Journal of Family Practice*, 1977, 4, (6), 1057-1060.
- Collins-Moore, M.S. Birth and diagnosis: A family crisis. In M.G. Eisenberg, L.C. Sutkin, & M.A. Jansen (Eds.) *Chronic illness and disability through the life span: Effects on self and family*. New York: Springer, 1984.
- Friedrich, W.N. Ameliorating the psychological impact of chronic physical disease on the child and the family. *Journal of Pediatric Psychology*, 1977, 2 (1), 26-31.
- Gardner G.G. and proposals. Adolescents with cancer: Current issues *Journal of Pediatric Psychology*, 1977, 2, (3), 132-134
- Georganda, E.T. Thalassemia and the Adolescent: An Investigation of chronic illness, individuals, and systems. *Family Systems Medicine*, 1988, 6, (2), 150-161.
- Kellerman J., Zeltzer, Ellenberg L., Dash J., & Rigler, D. Psychological effects of illness in Adolescence. I. Anxiety, self-esteem, and perception of control. *Journal of Pediatrics*, 1980, 97(1), 126-131.
- Mattsson, A. Long term physical illness in childhood: A challenge to psychosocial adaptation. *Pediatrics*, 1972, 50, 352-356.
- Penn, P. Coalitions and binding interactions in families with chronic illness. *Family Systems Medicine*, 1983, 1(2), 16-25
- Tsiantis, J., Xypolita-Tsiantili, D., Papadakou-Lagoyianni, S. Family reactions and their management in a parents' group with beta-thalassemia. *Archives of Disease in Childhood*, 1982, 57(11), 860-863.
- Velasco de Parra, M.L., Davile de Cortazar, S., & Covarrubias Espinoza, G. The adaptive patterns of families with a leukemic child. *Family Systems Medicine*, 1983, 1(4), 30-35.
- Walker, G. The pact: The caretaker-parent ill-child coalition in families with chronic illness. *Family Systems Medicine*, 1983, 1(4), 6-29.