THALASSEMIA:

HOW DOES A CHRONIC ILLNESS AFFECT THE PSYCHOLOGICAL ADJUSTMENT OF AN INDIVIDUAL

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Adjustment to life is a function of our personality and the situations with which we are faced. The presence of a chronic hereditary disease like thalassemia is undoubtedly a serious crisis that confronts the individual from an early age. It presents the individual with a great challenge in terms of his/her adjustment. But why? Is it because individuals with thalassemia are inferior or have something «wrong» with them, as the majority of people believe? The issue is not one of inherited inferiority but one of acquired. An inferiority which is the result of the prejudice of society and the difficulty of parents to deal with it. But let us see the impact of the disease on the attitude of parents and other significant people in order to understand the realistic and unrealistic problems that an individual with thalassemia has to deal with, has to adjust to.

When discussing psychological development we know that what can cause problems in one's normal development is:

a. Early deprivation,
b. Pathogenic family patterns,
c. Early psychic traumas and
d. Inadequate preparation for adolescence.

When we talk about early deprivation we mean either the complete absence of a mother or the lack of sufficient mothering during the first and most important years of one's life.

Pathogenic family patterns mean a parent-child relationship that is either rejectful and critical or overprotective and overindulgent but also of parents who do not discipline or are inconsistent in their discipline with their children. Pathogenic family patterns also refer to intense sibling rivalry, faulty parental models, marital problems and in general the faulty patterns with which the family members interact with one another, or with which the family interacts with the outside world.

Early psychic traumas imply that the individual has been confronted with a traumatic situation early on in life and finally inadequate preparation for adolescence means that the individual has not been sufficiently prepared to face the demands of growing up. That is, she/he has not been prepared to form a separate identity, to be self-sufficient, to value himself/herself, to have goals and aspirations for the future, to feel competent to take on adult responsibilities and to live a complete and satisfying life.

Research has shown us that the presence of a chronic and/or life threatening illness may cause, or aggravate, any or all of the above problems. Let us briefly examine why and how the presence of thalassemia can intensify all these problems.

Diagnosis of the disease is a devastating, heartbreaking and earthshaking experience for the parents (Bruhn, 1977, Collins-Moore, 1984, Friedrich, 1977, Georganda, 1988). Diagnosis usually occurs early on, within the first year of life. Very often parents react with intense grief, feeling sad, depressed, guilty, disappointed etc ... It is thus possible and human that the mother and/or the father will be unable to provide the necessary, or the appropriate mothering resulting in some kind of early deprivation.

The diagnosis also brings a change in the parents' relationship with the child (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 that she/he can 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. Do not talk to friends about the illness fearing that they will be rejected, and thus 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 wich lead to a poor self-image and to feelings of depression and hopelessness.

When, talking about early psychic traumas it is evident that the young child that has thalassemia experiences quite a trauma. Body and mind are not two unrelated entities but they are one interacting system. When the young child has to deal with numerous doctors and nurses that often neglect to pay attention to how the child feels but look only at the body; when the young child has to deal with strangers that inflict pain that is often unexplained; when the child has to deal with stress that is beyond his/her grasp and understanding we can only talk about TRAUMA.

With all that has already been mentioned it is really a miracle to think about how many of the adolescents with thalassemia are able to successfully meet the tasks of adolescence; to form a separate identity, to be self-sufficient, to value hemselves, to have goals and aspirations for the future to feel competent and live a satisfying life. How are they capable of doing it? Although the presence of a chronic hereditary disease like thalassemia poses numerous problems to the individual it can also be seen as a great advantage.

For the Chinese the word crisis is written with two symbols: danger and opportunity. It is a threat that has to be dealt with but it is also an opportunity for growth. This is how a chronic illness can function when it is not constantly perceived as a misfortune for the individual.

Unlike many individuals of his/her age the individual with thalassemia is asked to confront a serious crisis from an early age. When parents do not become too incapacitated by their feelings of loss and grief, when they do not transfer on to their child their fears and the prejudices of society but help him/her to see it as *just an illness* with which they have to learn how to live; when they treat the child as a normal individual with a health problem and not as an incapable, inferior individual, the illness can function as a growth promoting experience. What can be more demanding to an individual than a physical illness? When the individual learns how to cope with such a demand she/he is capable of dealing and successfully solving almost any problem in his/her personal life.

In the final analysis, although thalassemia or any chronic illness is a difficult problem to deal with, it should not be viewed as «God's verdict» for a miserable existence. Human beings have proved many times in the past that they are capable of dealing with more misfortunes than we can imagine. So can an individual with a chronic hereditary disease when she/ he is provided with support, love and acceptance for who she/he is. Having a physical illness is nothing to be ashamed of and nothing to feel inferior for. This is however, an idea that has to be first understood and accepted by parents, relatives, doctors and nurses and then by the child. It is all who are involved with individuals with thalassemia, and of course thalassemic individuals themselves, that have to change the way with which society views them. In order to do so they have to believe it themselves.

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