THE IMPACT OF THALASSEMIA ON BODY IMAGE, SELF IMAGE, & SELF ESTEEM

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How much do we value ourselves, how much do we really like ourselves? Have we really come to terms with who we are, how we look, what we have? Issues of self-esteem and self-worth are central to our psychological well being but also for how much we care for, and pay attention to, ourselves and our bodies. How much we like and value ourselves is closely related to how we view our bodies. We all have misgivings about our bodies. Some of them are realistic and a lot of them are unrealistic. For many individuals, having a crooked nose, or small eyes, being a little too short or a little too fat can be devastating to their self-image. Consumer society places a heavy emphasis on body-image for one's success as an individual. Body image is closely related to self-image. How should then a chronic illness like thalassemia affect body-image and self-esteem?

One of the most potent sources of stress is physical illness. When we are ill, even when we have the flu, our body suffers, we suffer. We cannot do all the things that we used to do and more importantly, we do not FEEL like doing too many things. When our body is ill, it causes us pain and frustration, it is the source of anxiety and suffering. The question is always "when will I be well again?". For the individual with a chronic illness however the answer is very bleak." You will never be well. You will always carry this illness with you. The illness is part of you". This is a very difficult idea to accept. It is not easy to incorporate the presence of the illness in your self-image and feel good about yourself. To the ears of the novice it may sound as a contradiction. Is it possible? Can it be that your body causes you pain and frustration and yet you like it and you take care of it?

The question becomes even more complicated when we think not only of the realistic hardships that a chronic physical illness presents to the individual, but of how this individual is treated and viewed by others. For many years the presence of thalassemia was identified with, and often still is considered as a "stigma", as a source of inferiority. The individual is not a person with a physical problem but a weak, incapable being for whom we feel sorry and to whom we offer our sympathy. Thus, what is incorporated in one's self-image is not only the physical illness but also a specific view and a specific attitude towards one's self. The internalized image of an inferior individual. Is this inferiority a realistic one? Does it mean that an individual with a physical illness is a weak and incapable being?

A review of the literature informs us that quite a few changes occur due to the presence of a chronic illness. The diagnosis of the disease is a devastating, heartbreaking, and earthshaking experience for the parents (Georganda, 1988, Collins-Moore, 1984, Bruhn, 1977, and Friedrich, 1977). Very often parents react with intense grief, feeling sad, depressed, guilty, disappointed, etc… The diagnosis also brings changes in the parents' relationship with the child. They may become critical and rejecting or they may become overindulgent and overprotective limiting the child's already restricted functioning. Very often parents become 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. As a result of feeling neglected and left out intense rivalry and/or psychological problems may develop in an attempt to draw the attention of the parents (Penn, 1983, Velasco de Parra, et.al.}1983, Walker, 1983, and Mattson, 1972).

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. 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 (Georganda) 1988, Tsiantis, et.al., 1982). 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 s/he can develop an adequate self-image and self-esteem (Blumberg, et.al. 1984, Kellerman et.al. 1980, and Gardner, 1977).

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 treated differently. Thus, they often do not get involved in all the normal activities of their age. 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 which lead to a poor self-image and to feelings of depression and hopelessness. Is this bleak image that is presented to us reversible? Can it be that an individual with thalassemia, or with any chronic illness, feels good about himself/herself? Can it be that an individual with a chronic illness adjusts and successfully copes with this difficult problem?

Julia is a 28 year old woman with thalassemia. She has been in therapy for two years. When she first entered therapy, she related that her most important issue was her relationship with her body. "I don't have a good relationship with my body. I don't like it". She stated her goal as follows: "I want to feel stronger; I want to feel that I can shape situations without them shaping me. When I meet with difficulties I quit ... I get easily disappointed".

During the first year of therapy Julia discussed primarily her difficulty in expressing herself; expressing how she felt and what she thought because of her fear of being rejected and criticized. In addition she always felt guilty when she tried to defend herself and what she wanted and needed as if she did not deserve to have what she wanted. Her view of herself was that of a sick individual who was unwanted and unattractive. She felt that her own family devalued her and did not believe in her. She was very angry about it but never expressed it openly.

Suffering from a low self-esteem and a devalued sense of self Julia always looked for approval and acceptance from others. In her relationship with men she also wanted approval and affirmation of her femininity. However, she felt very easily hurt and rejected and she believed that the only thing she could offer to keep a man was sex. Yet, she did not enjoy her sexual relationships because she did not feel comfortable with her body. Furthermore, she believed that her partner would not like her body and general appearance, although she had no physical deformities.

When dealing with her feelings of weakness and vulnerability Julia related that the overprotection of her mother made her feel weak and fragile. Why would she otherwise be so worried about her? She always received the message that she must be very careful with everything she did because it would be very easy for her to "break". She was able to realize that this was what she now thought of herself, how she carne to view herself. Every time she would take a risk, either physical or emotional, she would feel she was in danger of breaking down, of hurting herself.

Julia's fear of being hurt, of causing damage to herself, of dying, was a very important issue that prevented her from enjoying life. She experienced great difficulty in expressing herself and her fears and used to somatisize all of her problems. Whenever she did not feel well and wanted to cry, she would hold it back and would instead talk about a terrible pressure she had in the chest, how her stomach felt bloted, how much her spleen hurt her. Julia related that when she was growing up, her illness was the only thing that her parents, and other adults around her, seemed to take seriously and it was only somatic complaints that she could express and draw the attention of others with. Quite the contrary. The expression of emotions was something that was prohibited. The family never spoke openly about how they felt in general or about the illness.

Part of the therapy focused not only on her relationship with her parents who viewed her as fragile, different than the rest of the family and in need of their constant support and caring, but also on her relationship with doctors and nurses. They also seemed to reinforce this view of her as fragile and in need of special treatment. However, what was even more painful was that they did not seem to "see her". They just saw her body and its vulnerabilities. They took care of her body but never asked her how she felt. Julia realized that she had always been afraid that others would not "see her", would not care about how she felt and, even more, that she should not say how she felt.

As she slowly became more able to express her pain and sorrow about her condition, her feelings of weakness, fragility and inferiority, her somatic symptoms were reduced but she was then hunted by nightmares. Nightmares of falling, of hurting herself, of dying, of being alone. Recently Julia had a dream. She dreamt she was naked and her body was the object of observation. She felt very ashamed of her existence. She related that she realized how much she hated her body because it made her suffer; how much she hated her existence and how afraid she was that she would be self-destructive and hurt herself. She was experiencing a lot of sorrow and despair. It was, however, the first time that she could express so openly how terribly she felt, and was able to cry in the presence of another human being. Since then Julia has been expressing more and more her concerns, her anxieties, her fears, her difficulty in reconciling herself with her body. She has been able to be more open and expressive with her friends and especially her boyfriend. She complains less of physical issues and has started smiling more often. She speaks with a voice that is more self-assured and is seriously thinking of starting a small business.

Iphigenia is a 30 year old woman with thalassemia. She has been in therapy for three years. When she first entered therapy she wanted to learn more about herself and her relationship with others, primarily men. She related she had an image of a big castle which she was about to enter. She was very scared of what she would meet inside. Monsters and huge spiders and all sorts of scary things. Iphigenia, like Julia, had great difficulty in expressing her feelings and her concerns. It was very difficult for her to express her anger and her resentment for her condition because she was afraid that others would reject her. She had learned that she had to be brave and strong in order for others to approve of her and she never wanted to show that inside she felt weak and vulnerable. She needed to be in control and could not relax because if she did she was afraid she was going to be self-destructive and would hurt herself. That if she let go, she would slowly but surely kill herself by not doing what she had to do, by neglecting her medical treatment.

As therapy proceeded, Iphigenia was more able to express her feelings of weakness and vulnerability; her deep concerns about dying and about not having enough time to do what she wanted to do. She became very angry with others and resented the fact that she had to suffer so much whereas they did not. She resented the fact that she never lived a care-free life. Even as a child she had to be always aware of when she had to go for a transfusion, had to remind herself of using her desferal, had to make appointments with doctors. Her life was full of hurdles that she had to overcome and she often felt very tired of taking care of herself. During such times she would get depressed, would not use her pump, and would just hang out with friends endlessly talking about whether there was any meaning to life.

Iphigenia related that one of her greatest fears in expressing herself and her feelings to others was that they would not take her seriously. She felt very deeply hurt when she opened up and felt that she was not understood, that others did not CARE to understand. As she proceeded to explore this issue, Iphigenia realized that one of her most important traumas came from her relationship with doctors and nurses. She remembered how she felt as the object of observation and how hurt she was that they just looked at her body. They did not "see her". They just saw her body. They did not care to see her but only cared about the body. This body that she hated so much because it was the source of all her misery.

It was not until much later in therapy that Iphigenia was able to reconcile herself with the idea that she did not like her body but it was still the only one she had. She did not like what she had and what she needed to do in order to keep fit, yet she liked herself. She believed that her illness gave her a wisdom that was far beyond her age. She was able to realize that life is valuable and that life is what we make it to be. She did not want to waste any of her precious time. She wanted to be productive and to live as fully as she could. Iphigenia is now a successful woman, admired by her colleagues for her liveliness, her endurance and her ability to solve problems and deal with frustrating situations that incapacitated them.

Julia and Iphigenia are two examples that can help us understand a number of important issues:

A. **HOW THE ILLNESS IS PERCEIVED & DEALT WITH** by others, parents, doctors and other significant adults may cause more of a problem than the illness itself.

It is very important to understand that the child is greatly influenced by how adults view him/her. Our self-image and self-esteem is to a large extent dependent on, and affected by, the perceptions of others. When your own mother and father view you as a weak and vulnerable individual it is more than likely that this is how you will also think of yourself.

When parents overprotect or do not discipline their child; when they do not allow it to do all the things that a healthy child would do they indirectly say to the child: "You are vulnerable, you are fragile, you are different from the rest of the kids". This difference is translated in the mind of the child as something "less than others". Parents have to be supported and taught how not to transfer to their child fears and anxieties that they experience. Some of these fears and worries may be realistic, a lot of them however have nothing to do with the actual condition of the child but with our misconceptions of how terrible it must be to be ill; with our own fear of death and vulnerability.

In this respect doctors and other health care providers could be of immense help. Yet, they very often make things worse since they are themselves not well informed or are thinking too much of the child's physical well being neglecting to think of his/her emotional wellbeing. It is a common complaint that doctors "give lectures and tell us what to do but they do not know everything". This everything has to do with the child's psychological state. It is easy to say that you must use your pump everyday but it is very difficult to empathize with what that means for the individual. What a struggle it is to constantly do what you HAVE to do and you DO NOT WANT to do. Compliance with medical treatment is something relatively easy when the child is young and the parents cooperate. It is very difficult however when we deal with teenagers that anyway do not want to comply to anything and with adults who do it because they HAVE TO, although they do not care, and not because they WANT TO LIVE. The question then arises: can we help someone to want to live?

B. **HOW & WHETHER OR NOT FEELINGS, WORRIES & CONCERNS ABOUT THE ILLNESS ARE EXPRESSED** is of immense importance.

Life without emotions is like food without spice. When we are unable to experience our feelings and express them, it is doubtful that our life has much meaning. It is important for all people to be able to express themselves. To say how they feel and what they think. Very often however we do not express ourselves because we are afraid. One of the most common fears is that we will be rejected or not liked by others. The individual with thalassemia often faces an added complication. Discussing feelings and thoughts about the illness is taboo. We all know but no one speaks. This secrecy is a very common phenomenon in other taboo areas like incest or child abuse. The message is that this is something "bad" that must not be discussed with others and/or the family. It is also important to remember that in the case of abuse and incest the blame is often placed on the victim and is internalized. "If I had been good enough dad would not have beaten me". "If I had not been provocative I would not have been harassed". One has to wonder whether the question is not raised for the ill child too. "If I had not been bad I would not have been punished". Having to go to the hospital for these painful procedures what else could it be than a punishment for unknown sins? Sins which often the parents themselves feel that they are haunted with and for which they are punished through the ill child.

C. **FEAR OF DEATH, ANXIETY, ANGER & DEPRESSION** are common and say nothing about the mental health of the individual.

George Vaillant (1977) in his book *Adaptation to Life* wrote:

> *... The mentally healthy are by no means immune* to *anxiety and depression. This is because healthy adaptation requires an accurate perception of the universe and accurate perception often evokes pain ... The reliable presence of people who love us facilitates our perception and toleration of painful reality and enriches our lives. Soundness is a way of reacting* to *problems not an absence of them.*

The presence of a chronic hereditary illness, like thalassemia, is a very demanding condition that will unavoidably cause a number of intense emotional reactions. The accurate perception of the implications of such an illness cannot but create feelings of anger and depression, fears and worries. If the individual does not experience them s/he is not in touch with reality or is refusing to deal with the reality of his/her condition, in which case we would talk about a maladjusted person. The issue then is how one deals with these emotions. A first important step is that we allow the individual to have them. To experience them and to express them.

It is the parents, the doctors, the nurses and all who care for the wellbeing of the individual that have to look not only at the body but also to CARE about how this person FEELS. From research with cancer patients who are dying we know that it is not the dying person who does not want to talk about his/her imminent death but it is we who "care" about them who cannot tolerate to talk about it, who cannot tolerate our fear of death (Kubler-Ross, 1969). The same applies with chronically ill individuals. They know that they are ill and are dealing with it, since they anyway cannot do otherwise. They need to talk about how they feel but they have not learned how to since everyone has always been avoiding such discussions. We usually avoid to discuss something that we are afraid of, something that touches on our fears. Understanding that these feelings are normal and it is all right to express them greatly reduces their impetus. Whatever is left unspoken, half hidden, or unconscious acquires a tremendous power over us and guides us.

D. **THE PRESENCE OF A CHRONIC ILLNESS CAN BE GROWTH PROMOTING** if it is not viewed as "God's verdict" for a miserable existence.

No one can deny that the presence of a chronic hereditary disease, like thalassemia, is a serious problem and a serious crisis that confronts the individual and his/her family from very early on. However, we must remember that for the Chinese the word crisis is written with two symbols: danger and opportunity. A threat that has to be dealt with but also an opportunity for growth. For George Vaillant (1977):

... Serious physical illness may contribute to *mastery of life. Thus, inner processes can erase* or *magnify the effects of external illness. Health and the "ego" must be considered together.* Furthermore, he wrote that *... an outstanding feature of successful adaptation is that it leaves the way open for future growth.*

The question then is raised: How can we successfully adapt to the presence of thalassemia? Taking into consideration all that has been mentioned before we could say that the single most important factor is our <u>attitude</u> towards what we have. How the illness is viewed and how it is incorporated into one's self-image. Is it that <u>we are</u> ill or is it that <u>we have</u> an illness? In other words is it that we are ill and thus weak, fragile and all of the rest of our misconceptions, or is it that we have an illness, which implies that we are in control of the situation? Very often the presence of the illness overpowers all other aspects of the individual's functioning. S/he becomes the illness. However, it is always important to remember that we are what we <u>think</u> we are. When we equate our existence and our self-image with what we have, we say that this is <u>the most</u> important thing, we give it the power to control us.

It is the responsibility of all those who are involved with thalassemia and of course individuals who have thalassemia themselves to realize that the illness is not the most important aspect of their life. Life is much more than an illness and when one is able to deal with such a difficult problem s/he is able to deal with all of life's problems. When we are able to face the unavoidable reality that we will die, when we come to terms with our existence, we can start to LIVE A MEANINGFUL LIFE.

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