

PSYCHOSOCIAL BURDEN

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When I was asked to present something on the psychosocial burden of the thalassemic I really did not have any idea what to write. I was actually tired of talking about psychosocial issues. As I started writing and thinking about the presentation I realized that after a while I was talking about a burden. The burden of living with something chronic and having to deal with it every single day of the year without the prospect of recovery but just with the hope of no other complications which often seems doubtful. I have often talked with my friend Lena who also has thalassemia and is older than me how tired we both feel. Tired of not the illness per se but everything that is involved in keeping healthy. Especially keeping our spirits high. So this presentation is dedicated to her, her strength and our endless conversations as well as to all the thalasseemics who fight everyday for a better life. I will keep my presentation short so that we have time to discuss all the questions and issues that are raised.

Just as recently as twenty years ago a new field in psychology was being created. It was the field of Health Psychology. Today it has become one of the most active areas within psychology. No one anymore doubts that behavior is a basic and influential component of health and it can make disease more or less likely. Diet and drug use, exercise, stress and other behaviors have demonstrable effects on a range of physiological systems and health outcomes. Disease processes such as those involved in cardiovascular disorders and hypertension, deficiencies of the immune system, respiratory and dermatological problems are clearly tied to behavior and to emotional experiences. How people behave when they are ill, whether they seek medical attention and whether they comply with specified treatments also determine the eventual costs of a disease or the severity of its impact. Health and illness are related to what we think, feel and do and there are exciting and significant new areas of investigation that need to be pursued.

In health psychology the biomedical model which prevailed in the past and which viewed mind and body as two separate entities, has been replaced by a more holistic approach called the *biopsychosocial model*. The biopsychosocial model considers psychological and social determinants of health and well being along with more traditional biological factors. Biological factors, including bodily processes that promote disease and genetic predispositions that may contribute to them, interact with psychological factors and social variables and these interactions have pervasive effects on health.

Social factors in this model would include personal relationships, one's sense of community and social support and one's socioeconomic status whereas psychological factors range from mood to self-esteem and coping styles. Together these factors determine one's health and well being.

The medical community is becoming increasingly more aware of the importance of psychosocial factors in issues of health and illness. Research evidence shows for example, that anger, anxiety and depression are important psychosocial factors that contribute both to the initial cardiovascular problem as well as to the potential for recovery from such problems. Our health is influenced to a large extent by what we think and feel. The power of positive thinking is discussed at length in the literature for healing. Healing not only emotional, psychological wounds but physical as well (especially in orthopedics). This very potent drug however is not only left unused but even more importantly is not at all cultivated.

Positive thinking is very closely related to how we feel. Actually for many theorists it is hard to distinguish whether it is the chicken or the egg that comes first. Is it that we feel well so we think positively or is it that we think positively so we feel well? No matter what comes first we know for a fact that both feeling and thinking are intimately connected, as intimately as body and mind. The one affects the other in powerful ways. Cognitive behavior therapy is a psychotherapeutic approach that is based on the basic notion that if you change the cognitions—the way someone thinks—you will also see a change in the behavior and the mood of this person. Actually research evidence supports 100% this belief of cognitive behavior therapists.

I must say, however, that in my experience in order for someone to visit a psychologist and start psychotherapy one of two things need to happen. Either things get very bad and the person is really suffering severely or the person somehow cares enough about him/herself to want to make his/her life better. As Bernie Siegel a surgeon, writes in his wonderful book "Love, Medicine and Miracles" (1986): "The ability to love oneself, combined with the ability to love life, fully accepting that it won't last forever, enables one to improve the quality of life." (p.4) This quality of life, is what we are seeking for for many years. However, as we grow older and wiser we realize that for any significant improvement to happen in our life we need to work very hard in order to gain it.

For example, I know from myself that smoking, drinking, driving fast, partying till morning were all ways of proving that I was one of the gang, that I was no different from other teenagers. We are no different from other human beings. So what we do, how we think and feel affect our well being as much as any other human being. The bad habits we have acquired in our teenage years are hard to break. It is difficult to really acquire new healthy habits because it requires a lot of self-discipline and self love. Self-discipline which, at least, I feel that I have used up in trying to comply with everything I have to do for my health. Transfusions, pump, appointments with doctors where you have to wait for hours as if you have nothing better to do with your life, disrespect of my intelligence and sensitivity from nurses and personnel,

bureaucracy for getting my medications and doing all the paperwork required for everything, are all things I hate but I still have to face and do. So when it comes down to doing things I have to do because I want to make my life better, like eating well and exercising and taking time off and having fun I have no strength and no self-discipline left. I have no desire to do anything any more.

If we want things to change however we have to work hard and most importantly we have to think highly of ourselves and not underestimate our powers and the control we have over our life. It is true that as kids we are not given much control and cannot really have much control. But we are no longer kids, we are no longer “the children”. As grown ups we have to try to change our unhealthy habits, we have to make our everyday life better. We cannot blame others for everything that goes wrong but we also have to show to others what they do wrong in the way they treat us. This sometimes makes us “difficult patients”. We are difficult patients. Every chronic patient is a difficult patient. Primarily because as someone with experience we know what is going on. A person who lives with a life long problem is not like the unsuspected patient who, for the first time walks into a hospital and is utterly lost. We are accustomed to hospitals; we are not afraid of needles and white blouses. We know when our vein is broken or when a nurse or a doctor does not know how to put a needle in. Whoever is a suspected customer is a difficult customer. So no doubt we often give a hard time to the doctors and the nurses. We are difficult patients for another reason as well. Because we are TIRED. Tired of waiting and waiting at doctors’ offices and hospital corridors. Waiting for tests, waiting for blood, waiting for new developments, waiting in line to get this paper and the other official signature. I wish I no longer had to wait. I know this is not possible. I know doctors and nurses are also human beings and they are also tired. Tired of seeing our faces every so often, of facing their difficulties with their work, of having to live with their problems, dissatisfactions and limitations. So we are difficult patients and they also have difficulties. Communication channels need to be opened. We have to sit and discuss how things can get better but not so much in terms of medical conditions but in terms of human conditions.

As I mentioned in my presentation at the medical conference, health psychology provides ample research evidence that hostility—which is defined as cynicism, mistrust, anger and aggression—together with stress, depression, social isolation and unhealthy habits such as smoking, drinking, etc. are affecting the cardiovascular system. They are not only causing heart disease but they are also poor prognostic signs for recovery from diseases. These vices and personality characteristics are definitely part of a large number of us thalasseemics. But the question is why.

Why are we angry? Why do we get depressed? Why are we so cynical and mistrustful, why do we have such poor lifestyle habits? Why do we get destructive and self-destructive? I know that for many years I was angry and I still get very angry when I am treated as an object. No, I am I and I demand respect. I try to do everything in my power to not offend and mistreat others because I believe that we all deserve to be treated well. I get furious when I

am taken for granted, and when it is taken for granted that since I am sick I can do no different than wait patiently for the doctor-God to come and see me when he is through with everything else he has to do. I get furious when it is taken for granted that I can do no different, since I am dependent on those who take care of me, than sit there quietly-- like a good girl-- and not complain although I am ignored for hours, or I am told at the last moment, the doctor cannot see you today and I have ruined my whole day and everything else I had to do that day in order to see him. I am a human being that suffers from a disease. But I suffer even more by the indifference and the disrespect of my personality.

We are no longer kids who will just do what we are told to do. We are grown-ups with strong personalities, and I might say sometimes too strong. We have to participate and equally share in the process of our well being. By now we know what our body needs. We know what makes our soul feel better. We need to respect our body and our soul and listen to what our inner self says we need to do. We need to be very careful however to distinguish whether this voice comes out of self-love or self-hatred. It was Sigmund Freud who in the beginning of this century gave emphasis to the death instincts as well as the life instincts that we have inside. We are not just all good. Evil forces exist too. We see it in the whole world around us. Actually death, destructive, aggressive impulses seem to be reigning the world these days. So I guess we are no different than the rest of the world. If, however, the world is to not self-destruct and if we are to stay alive and progress on an individual and universal level we have to learn how to turn the other cheek. I know how difficult it is but I also know how important it is to learn to let go of our anger and our resentment towards others-doctors, nurses, friends, family members- who mistreat us and forget that behind the body there is a soul. We have to learn to forgive others and to forgive ourselves for not being perfect and not being everything that we want them, and we want ourselves, to be. We have to accept our limitations and come to terms and at peace with who we really are and what we have. We have to get to the point where we like who we are and thus what we have because this is also part of us. When we reach this balance and this inner harmony, this acceptance of who we are, then we will acquire a much better physical health, despite the fact that we have thalassemia. Just doing what we have to do (transfusions, chelation, etc.) without liking who we are, without loving ourself and loving life and wanting to live, no miracles can happen.