Blistered Epidermolysis, the Difficulty of a Primordial Delimitation

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Much has been said about the body as a privileged object through which we delimit an internal and external world, an inside and an outside that paint individual characteristics and relational fields. We also know that subjectivity is constructed through the body as a representation scheme. But although we have accepted suffering as a never-ending source of questions and learning, our astonishment is renewed by the incomparable human capacity to repair what to us appears as the limit of what is tolerable.

Blistered epidermolysis is a heterogeneous group of chronic hereditary blistered diseases characterized by the formation of cutaneous-mucous boils which appear after minimal traumas. The fragility of the skin is manifested in all its forms, and in consequence the whole surface of the body is affected in its capacity as a tactile communicator as the principal means of relating to others.

If we base ourselves on Didier Anzieu's concept of the 'Ego-Skin', we can see that 'even before one's own selfness, a sonorous wrapping is formed, a bath of sounds that prefigures the ego-skin and its two-sided face turned towards the inside and the outside, since the sonorous wrapping is made up of sounds that are emitted alternatively by the surrounding medium and by the baby. In this manner the first space-auditive image of one's own body is produced'. This is a relationship that will mark the manner of exchange, a style, a greater or lesser capacity to permeability or impermeability at the start of emotions and affections that are felt as one's own, as a part of one's being. The maternal sounds and talking will be the carrier of a global sense, since the maternal role oscillates between biological and social functions. It prefigures the gradual insertion of corporal time into time objectivized by society. A society which beatifies values and ideals that do not always allow a person to insert himself into society comfortably – when his own concepts do not coincide with the concepts of beauty that are imposed on him.

We should also remember that those who suffer blistered epidermolysis will surely not feel acknowledged and appreciated on the catwalks of collective applause. The sensation of failure of those mothers and fathers whose children take the place of the 'deformed' is endless. Didier Anzieu continues: 'The ego-skin can lose its biological support in the skin. In its place, due to conversation, to the internal word and to the consecutive symbolizations, it finds another support, of a socio-cultural type. The ego-skin really functions through multiple support. The skin of words has its origin in a bath of words of the infant to whom the environment speaks to or for which he gurgles. Later on, with the development of verbal thinking, he is provided with the symbolic equivalents of sweetness, flexibility, and pertinence of the contact precisely where he had to renounce to the impossible, prohibited or painful touching.'

Yet, the organization or disorganization of the vicissitudes of the parents' affectionate life will be of utmost importance. Upon this will depend the capacity of mental functioning to link or model affections and convert them into instruments of creativity rather than into seeds of traumatic experiences; and also to transmit security and protection to the child even in situations of suffering.

These considerations lead us to understand that, on the parents' part, it is necessary to construct a global identity that implies an 'I am with the others, with the acknowledgement of the others towards me and mine towards the others, which are different'. This is the identity of the self, a style on a stage, a place to relate with others. Just like the immunological system this leads to a consciousness of the world, of one's own being and one's own not being and of being able to adapt our reactions of destruction or protection that lead to the integrity of one's own being. But that place of relating, that place of difference is already marked in these cases by the bitterness of the inheritance of the disease. Some mothers or fathers are af-

flicted by the disease themselves, so that it is difficult to find a place of appreciation for what has been created: the child that it is a prolongation of one's own suffering. Narcissism wounded doubly, narcissism hostile towards oneself and hostile towards the child.

The mother's discourse talks about her past or present pain, or her suffering, of her own epidermolysis, but it will be necessary that the thinking of the mother is able to invest her child, once she herself has been able to think about herself and invest herself, after having elaborated the weight of her guilt, of the impotence and the disenchantment towards herself and/or her child. Man is born with the possibility of making things and feelings consciously, and the Ego is the vehicle that links him with his emotional and corporal world. The Ego acquires its sense of identity from the perception of the body. Therefore, the mother will be able to make the pain tolerable, consoling her child, once she has been able to be a mother to herself. The mother's discourse is capable of repairing the biological skin for herself and also for her child. Because at stake are the identifying statements that mark the subjectivity of the child and that point out the risk of provoking the work of disinvestment towards oneself. This is also the point of support for the disvitalization and weakness in the relationship between the internal and external world.

The mother's discourse is full of her own private language – which makes reference to her own private emotions. Her words are connected with her sensations. This language shows the limits of her own world, since she cannot talk or think about what she cannot find within her own language. This is where the dynamics of intentions, expectations and desires are developed. It is there where the first accent on the analytical work must be placed, so that it can be discovered or recovered, according to what is most valuable for one's own existence in each case. Because the narcissistic pathology which is generally at stake in these cases, is centered in the underestimation of oneself, in the deception and in the erasing of a desiring being.

Andre Green would say that that neutrality replaces the pleasure of existing. The body has transformed itself into something that makes one suffer, that is looked upon as strange, yet at the same time one knows that one will have to bear with it without knowing why one is condemned to all this. If the organic suffering in the child as well as in the baby, which is also psychic, exceeds a certain duration, it will mark the hostile relationship with his body and with reality. Also, it becomes difficult for people who have blistered epidermolysis to feel that their body is protected from any accident that may occur. The skin, as a system of protection, has lost its place. Instead of feeling that one has an autonomous body, it feels more like one has a violent marionette interacting with those who are within his environment, a marionette which is dependent on the extreme and constant care.

Through directed and semi-directed interviews in psychosomatics with parents and their children suffering from simple

and dystrophic blistered epidermolysis, we have detected attitudes of family rejection or overprotection that have influenced the behavioral problems of the child. With the implementation of the guidelines of a protocol elaborated for the study, the vicissitudes of the disease, the feelings, and the sensations that collaborate in the formation of the corporal image and self-esteem of the mother, the father, and the child were researched, and we were able to see the importance of the voice as the organizer of corporal space. The voice is the first field where the child trains himself to perceive the differences between himself and others. The voice if lived as something agreeable allows the child to conform, to a greater or lesser degree, to a corporal space. It allows the children with blistered epidermolysis to live within their bodies with the least possible hostility.

The work in the hospital puts those who are dedicated to the field of health to the test. It teaches them to implement treatments with creative techniques that overcome the helplessness arising from the use of minimum resources, in a minimum time length, with a population of a very low purchasing power, in a society where globalization makes those unemployed feel that this is the common situation.

We turn to the sonorous envelopment that music gives. We believe that when a baby arrives to this world he is 'dressed with clothes and with words'. So these patients are caressed with the voice. We know that a 3–8-week-old baby orients itself to the location of the mother's voice, and his corporal identification begins from this voice even before the use of words. The voice is the first field where the baby trains himself to perceive differences. The tone, the accent, and the gesture that accompany the voice reinforces the meanings. The voice belongs to the body and it is separate from the body, transforming itself into an object that is different from it. It is emitted and heard. Thus the images of shouts, cries, and melodies that enter and leave are articulated. Each being can create its own melody. On finding and making one's own song or melody, when one hums it, having it to oneself, in some way one is also creating it. The way towards this quest is our task: Recognizing pain, but learning from the strategies of survival, the dimension of each individual's capacity of creation. It will redirect the suffering into the emergence of a creative skin that turns the cries of anger into melodies.

First, the proposal is that a rhythm, a song, a type of music, jazz, folklore, classical, be found for the different types of moods. Then we ask that a song, or music that they identify themselves with be chosen. We take into account and make it known which are the different postures and gestures adopted in each case according to the above-mentioned moods. We remember that the skin (in this case particularly severely affected) also has its own language with respect to this; what is corporal also includes writing, talking, listening, dancing. The meanings flow in the exchange with others. The relational field starts to change its hard tone and just like the transitional object, mine and yours, internal and external, the voice, me-

diated by the music replaces ecotactile communication and it becomes a moment of encounter.

There is a correspondence between the interior and what is heard, a sonorous matrix that becomes tactile through a common quest, and that sets out as a pleasant flash in the continuity of displeasure. A pleasant flash that will allow us, very slowly and by our own means, to find a small part without an atrophy in the corporal space and in the relational space. If the child is less than 3 years old, it will be the mother, the father or both (if possible), and the child held in their arms who will enact this proposal. It will depend upon how over-adapted they are towards their disease to make this possible.

In parallel we have to unmask the deceit that it is impossible to modify the tyranny of the roughness and abruptness as the only means of relating to oneself and to others. The process of this quest promotes the necessity of a family link that in itself will be different from that which is habitual, where in general the tyranny of roughness and abruptness as a mode of relating to oneself and others is dominant.

It is known that narcissistic faults crystallized in external lesions reflect the internal image of devalorization, and that the

insufficiency of the family structure leaves existence alienated in a river of irritation, whose waters will grow due to the desperation that is generated by situations of conflict.

We propose a maternal-type environment that surrounds the child with a sonorous wrapping given also by the music that will re-signify the biological skin that is seriously affected. In this manner we help to construct a better quality of life by helping the patients to live with their disease in chronic situations.

With this proposal and working with these patients, I must admit that I became quite emotional at times, while at other times I suffered because I could not achieve what I had proposed; but in all the cases I tried, and to different degrees succeeded, in making the voice a caress.

References and Further Reading

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