

## When a diagnosis changes life

Piergiuseppina Fagandini

In our current society it seems that in order to reach the maximum efficiency, even in the sanitary field, we are forced to loose contact with the emotions becoming therefore omnipotent.

Technology, even within the hospital, may become the impossible escape from pain. On the contrary, the possibility of recognising our own limits and impotence integrating technology and ethics at the same time, would be able to make pain tolerable and comprehensible.

The guiding principle of our work inside the hospital is that we can not let go situations if they haven't "belonged to us", if we have not been able to "appropriate of them".

It is a must to let pain or happiness go through ourselves to really be able to feel these emotions.

It is therefore necessary to offer a systematic and specific emotional preparation to all the sanitary staff. In the Infantile Neuropsychiatry and in the Neonatal Intense Therapy departments we do not just treat the ill children, but also their parents, their families. And it is their parents who often are able to teach us and to think and propose new ideas, in spite of the great pain they may be feeling as well. They deserve the sanitary operators' attention and careful listening which can just come from their internal attitude able to offer an emphatic relationship instead of just offering their technical abilities.

Sometimes the sanitary operators, more than anyone else, need to learn how to listen and how to feel those emotions that can just be guessed, narrated or kept in silence: the emotions and feelings which are not always comprehensible, not always tolerated.

We must learn to consider the ill children's parents not as patients but as people who, going through a very serious and traumatic situation, may need support either individually or in couple for the construction of their relationship with their own child.

Therefore we should avoid thinking just in psychopathology terms and concentrate our attention in the unpreventable mental pain than can later become a psychopathology if it is not properly listened, stopped and shared.

So far we have learnt that the sanitary operators always need to understand their own feelings to be able to provide help.

But for feelings we don't just mean "good" feelings.

Our mind generates metaphors based on the experiences lived in this world, tries to understand the events by building unconscious fantasies, games, dreams, stories.

Our mind lives from the richness and truth of its own symbolic constructions. If there is no symbolic development or if the symbols do not match the emotions that were able to create them, our mind "dies".

We must accept our limits but we also must look for new ways - sometimes even a poetic path - to try to get an understanding between the children, their parents and the sanitary operators to continue living, growing and working altogether.

### Birth

She lies on the bed exhausted, worried, in silence. Staring out of the window...

"You were great".

*She denies with her head.*

*"Don't worry. It will be OK, you'll see".*

She doesn't answer.

..... "Have you already seen the baby?"

*"No."*

*"Go to see him."*

*Who has told me about birth happiness?"*

G.Pontiggia *"Nati due volte" (Born twice)*

### Mothers

*" What unsettling strange thing  
when mothers start vacillating..... "*

S.Freud

Talking about "healthy" children's mothers: pure love without ambivalence is just an illusion based on denial.

Loving a child, any child, also implies accepting feelings such as fear, anger, rage, hate.

Hate also means life and it is a feeling that divides but which needs to be faced without too much embarrassment nor too much fear.

Winnicott, who before becoming a psychoanalyst was a pediatrician, illustrated at least 16 good reasons a mother has to hate her own child. I will list three of them using Winnicott's words:

*.....yet the mother hates her own child since the very beginning:*

- *The child represents a danger for her body during pregnancy and birth.*
- *The child represents an interference in her private life, he/she is a challenge to her previous life.*
- *Every mother has the feeling that her own mother demands a baby from her. Therefore the child is done to satisfy the woman's own mother's demand.*

In tales the "good mothers" are those who disappear, succumb or pass away.

The feelings towards a sick child are dominated by rage, embarrassment, hate, but also by tenderness and pure love.

Telling our emotions may be helpful to tolerate and it can be therapeutic too.

*.....it is extremely difficult to bring the memories of his childhood to my mind, they remain drowsing because if I think about them the pain is too much that makes me cry. But I also cry if I think about the good memories such as pregnancy or the dreams I used to have... After that I panicked... it is very difficult to explain how these two strong emotions took turns to come into my life. It was supposed to be the happiest part of my life so, what was going on? My great dreams full of extreme happiness, congratulations, kisses and security had become a nightmare full of horrible ghosts. I hated the doctors, the nurses and any person who came next to my little boy saying that there was something wrong. I would have wanted to denounce them all and to tell them that it was all a mistake, that it was not me the one to whom should be communicated all that fear and pain. Later I also hated the child and I was not able to understand how in that little body could be the presence of such an ugly thing with no name ... I truly think that the parents' pain under these circumstances is totally unbearable and therefore it becomes easier to treat the child rather than his/her parents. It is a pain that*

*makes you feel empty inside, that gives you the feeling of being incapable of fighting.  
Someone once wrote a poem to me which has been present all these years, making me strong ...  
A mother*

## The fathers

*Sometimes I see him far away in the long, narrow street where I live.  
He walks leaning on the walls of the houses...  
Some people recognise him and say hello to him... But I deduce they treat him like a child. They  
are the same people that often treat children like idiots and by doing so are able to establish a  
face to face relationship with them... Who sees him for the first time can not stop staring at  
him, they stop and turn back to see him again. He realises about it and starts walking with a  
suffering gesture. But thinking about it better maybe this is not true as long as he is just  
concentrated trying not to fall, because he is used to being observed. It is me the one who is  
not used to it.  
I have a suffering gesture which is the one that brings us together through the distance.  
Who is that boy that walks vacillating leaning on the walls? I see him for the first time: he is a  
handicapped. I think of how my life would have been without him. No, I can not. We can  
imagine a lot of different lives but never giving up our own life.  
Once when I was looking at him pretending he was a different person and I were a different  
person myself, he said hello to me. He was smiling and was leaning on the wall. It was like  
meeting him for an instant but forever.*

G.Pontiggia "Nati due volte" (Born twice)

## The staff

It is necessary to take into consideration the "patients", their families and the sanitary staff's feelings considering them more as a resource than as an obstacle. It is necessary to focus their training in their own "cultivation" as long as they represent an unvaluable richness for looking after the patients.

It is necessary to provide them with formation and organization tools able to help the sanitary staff to recognise their own and the other's feelings, to name them and to educate them to bring them out in order and to "humanize" the professional dimension.

Not everything can be explained by reports and psychological interpretations, not everything can be "discussed". Sometimes facts can just be "narrated". Narration may help to heal.

## EMMA

*"I am OK only when you sleep  
when you are sleeping your pain stops  
it is so big, too big for your young life.  
If you sleep maybe you'll dream.  
Dream about the quite nest of a well-known belly that kept you  
making you feel so calm  
there where there were no bright lights nor strange sounds,  
where you were nested by a familiar big heart and there was a small heart  
that you can not forget.*

.....  
*And you shouted out with every single little part of your body*

*Obliged, tied up, abused, contracted. Sleep and from your long eyelashes  
let some tears drop out....*

*Your huge pain comes into me every single time I come next to you and enters into my soul  
cutting it, hurting it, breaking it down. I don't want to hurt you, my baby  
I just want to make you sleep. I am fine only when you sleep, if you are sleeping  
it seems to me that you are not suffering anymore.*

Paola Inf.Prof.

It is necessary to favour the assumption of the emotive life in all the professions, without delegating it just to the psychological or psychiatrist fields. It is also necessary to create a new service culture based on the importance of the relationships focused on help and recognising the main role that patients and their families have.

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