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GRIEF ELABORATION IN FAMILIES WITH HANDICAPPED MEMBER

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Summary. - *Families with handicapped member seem to follow the same five stages (rejection and isolation, anger, dealing with the problem, depression, acceptance) of Kubler-Ross grief elaboration theory while dealing with the narcisistic wound of a handicapped child. Some of these families show a block in one of the stages. The effort of psychotherapy is to remove the block and let them reach the last stage. In this paper families under systemic psychotherapic treatment are analyzed, who had in common the birth of a child with low or modest invalidating signs and psychotic or autistic features. The families structure did not show the characteristics of a psychotic family. Neverthless either one or both parents ignored the evidence of their child disease and they built a "disease-incongrous" wait around the child, trying to push away the painful reality. The authors explain the importance of this approach for the improvement of the autistic traits.*

KEY WORDS: systemic psychotherapy, autistic traits, mental retardation.

Riassunto (Elaborazione del lutto in famiglie con membro handicappato). - *Le famiglie con un membro handicappato sembrano seguire le stesse fasi (rifiuto ed isolamento, rabbia, confronto col problema, depressione, accettazione) della teoria di Kubler-Ross sulla elaborazione del lutto mentre affrontano la ferita narcisistica di un figlio handicappato. Alcune di queste famiglie mostrano un blocco ad una delle fasi. Scopo della psicoterapia è rimuovere il blocco e consentire il raggiungimento dell'ultima fase. In questo articolo sono analizzate famiglie che hanno intrapreso psicoterapia sistemica che avevano in comune la nascita di un figlio con lievi o modesti segni invalidanti e caratteristiche psicotiche o autistiche. La struttura della famiglia non mostrava le caratteristiche della famiglia psicotica. Tuttavia uno o entrambi i genitori ignoravano l'evidenza della malattia del figlio e avevano aspettative incongrue con lo stato del bambino tentando con ciò di allontanare la dolorosa realtà. Gli autori spiegano l'importanza di tale approccio per il miglioramento dei tratti autistici.*

PAROLE CHIAVE: psicoterapia sistemica, tratti autistici, ritardo mentale.

In a study of terminal patients by Kubler-Ross [1] the Author describes five stages in the elaboration of concomitant grief before passing over:

1) Rejection and isolation. - The patient makes use of this defensive mechanism to put out of his mind the idea that this cannot happen to him.

2) Anger. - When rejection can no longer be substained, in front of some events, the patient experiences anger, envy and resentment.

3) Dealing with the problem. - This is the shortest phase. The patient tries to find any form of compromise in order to find relief.

4) Depression. - When his disease becomes more serious, when the pain is more intense and he feels worse, he understands that he has no future, he must face the thought of dying, he must face to succeed in elaborating his pain.

5) Acceptance. - In this stage depression and nervousness disappear and the patient feels calm. He is tired and weak, he wants to die. His sleep does not mean to run away from reality, but to prepare oneself for the end.

Families with an handicapped member, free of psychotic component, seem to follow the same five stages to elaborate grief and narcisistic wounds represented by the

handicapped son. Some of these families show in the family therapy a block in one of the five stages, and the therapy allows them to reach the other phases [2].

Utilizing the above mentioned method we were able to observe that in this type of family there is disability "recognition" [3].

The family's perception of the problem in spite of the invalidating pain is that of "reality"; more or less functional answers are answers that respect/recognize the son's needs.

However we would like to focus our attention on families under treatment with a member presenting a graft symptomatology.

We want to underline that our analysis does not have a statistical significance, but we believe it is important to describe our works as an incentive for further investigations in this field.

The families treated have in common the fact that at birth the invaliditating signs were such that they would make either hope in a complete dissimulation or resolution of the handicap, or were not at all recognized.

G. is affected by such a mild form of Down syndrome as to have a face that cannot easily be noticed. The father, immediatly informed on the diagnosis, decides not to tell his wife "after all it is not noticeable"; she becomes aware of this eight months after birth.

M. is affected by hydrocefhalus, according to the doctors, so mild as not to require surgery or significantly interfere with the normal development. When M. begins to walk with a slight delay, the mother refers to the daughter saying "but your sister walked sooner"; M. now does no longer walk by herself.

Another common factor easily observed is that the "Ybris" [4], the fight for the final victory at all costs, rather than being carried out between the members of the couple, it is carried out between one or both parents and the disease.

The resolution to such tension is a total denial of the disease; any new positive behavior is seen as denial of the disease and not as a limited but possible step of its evolution.

In short we can see that in the treated cases where the handicap is either not evidenced since birth or minor, a "healing" wait incongruos with the disease is built around the patient.

This appears to be independent or at least stricly correlated to the family structure which does not seem to present the main characteristics of the psychotic family. Each member of the couple tries to push away the spectre of the ineluctability creating "convictions", and reading the signs of the handicap from a point of view far from reality. The individual, object of this incongruos expectation lives its own disability with ever increasing tension until - unable to respond to the family's requests - moves further and further away from the psychotherapist, choosing "the peace of not being" rather than the worry of the experienced rejection. In doing so he can put on the defensive the family who "made all possible sacrifices for the poor handicapped" and the psychotherapist with their project of "full recovery at all cost" [5].

The families proposed present a member with the following pathology:

G., 20 years, Down syndrome, autistic traits; L., 19 years, hypoacusia, cognitive deficit, cronic delirious psychosis; N., 7 years, agenesis of the corpus callosum, cognitive delay and severe personality problems; S., 13 years, moderate mental retardation, behavioral problems; M., 3 years, hydrocephalus, autistic traits. In the initial phase of the therapy, besides the usual gathering of information on the structural relationship of the family, and on the hystory of the patient, we focused our attention on the following areas:

1) at the time of birth, who was the first to know the problem, how long after birth, when was the diagnosis given by the doctors;

2) during the first period of development, what were the solutions sought by the parents; what organizations, what type of answer did they give;

3) when did the symptom explode;

4) what type of indications or diagnosis were made in relation to the symptom. What changes took place in the family since birth and after the psychotic simptomatology;

5) experiences and expectations on recovery possibilities;

6) expression of pain and rejection of the handicap.

As already stated the patients treated have different ages, therefore the type of investigation was made in relation to the phase in which the family is found.

Allowing this phase, which requires a longer time compared to other therapies, the second phase is centered on the patient's present abilities and potentials. In this phase the couple begins the long schedule of reconstructions of the expectations towards the son. In this phase the patient begins to give signs of modifications of the symptoms. The third phase is connected to the manifestations of the disability, to the evolution of the disease and chronicity. In this phase the parents learn to read the disability connected to the disease and the "sick" modalities with which the patient makes his requests. The symptoms attributed to the graft, become evident and are a result of the actions and behaviors of parents, psychotherapists, and external environment.

The final phase of the therapy with these families is utilized to discuss the future projects of the handicapped person in accordance with his irreversible disabilities.

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