



Caring for a Sick Child

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When a child is suffering from a serious, often fatal, acquired disease such as leukemia or cancer, or a genetic disease with poor prognosis, and thus is hospitalized for long periods of time, the uncertainty and unpredictability keep parents in a state of constant anxiety that is hard to deal with and difficult to control while maintaining a well-balanced behavior [1,2,3]. Many feelings are subconscious; others are the result of both the environment and of the information obtained from physicians and other professional caregivers. Discomfort, helplessness, and fear of death or permanent disability of the child are reflected and expressed by attitudes that are sometimes overprotective and other times are of refusal, waste, or anticipation of death. Sublimation often becomes a valid defense mechanism when the disease results in changes in the child's body or prevents him/her from leading a normal life. This high feeling allows and makes possible to mask frustration by developing highly social actions and psychologically rewarding.

The social status of the parents may play different and often ambiguous roles. It is well known that it is easier for families of lower social classes and cultural environments to involve the whole family as well as other members of their community, thus achieving valuable integration for themselves and for the sick child. In this context, similar to what is observed in less advanced ethnic cultures, disease and addiction are not considered shameful, but rather are accepted without difficulty. Most elite classes often reject and marginalize the parents and the child, thus resulting in reticent and false attitudes [4,5].

The relational balance that existed within the family prior to the child's illness, if acquired, or his/her birth, in case of congenital and / or genetic forms, is of fundamental importance.

Since ancient time's people have believed that a child's illness is punishment for acting outside the rules, disobeying, or carrying out illegal practices, often in the sexual sphere. These attitudes can lead to difficulties in accepting the disease.

The same traumatic experience with strong feelings of guilt may affect adolescents who suffer from acquired diseases. In this case, a positive and constructive relationship with both parents and continuity of care even during hospitalization is essential. The interaction between parents and children is just as important for the well-being of the parents themselves and to help them maintain their identity so as not to feel a decrease in their role as parents when facing the new relationships with physicians and other health care professionals in the hospital.

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The ability to maintain a continuous and valuable life balance both in the hospital and after discharge is not only useful but essential for coping well with the new cause of severe discomfort. This however may prove to be difficult if not impossible in cases of parents who divorced prior to the onset of the child's illness.

Even for pediatricians and psychologists this is a problem to be considered case by case, because there are no general rules. The sick child feels burdened with a new, even if occasional, sense of abandonment by one or both parents, he/she feels neglected and rejected because of this new and difficult life.

Late effects, such as insecurity, dissatisfaction, lack of affection, awe, fear of abandonment, and sometimes guilt feelings for past or present difficulties arising between parents and related to the illness may gradually set in. In the study of these feelings that increase during the illness it is important to try to understand the origin and to intervene with personalized psychotherapy.

Dependence and interaction between preschool children and their parents are always very strong, especially if a new situation such as a disease develops. Even under normal circumstances, older children or teenagers who regularly attend school, often have conflicting, tense relationships with their parents and with others (for example, their teachers) who try to interfere or influence their life choices.

The situation changes abruptly if they feel they are in real danger, if they go through a profound period of physical discomfort, if they suffer from a serious illness, especially if it is painful or requires diagnostic tests and complex care. In this case, children are attached to their parents and can become dependent, especially in the early days of hospitalization. Often it is hard for parents to find a proper balance, to cope with the situation that has presented, and to find the ability to talk to their sick child and to their other children with sincerity and honesty. It is not uncommon for parents to enter the burn-out tunnel, thus needing assistance and personalized care themselves.

Several studies have been carried out in the pediatric hospital world regarding the advantages and disadvantages of hosting mothers together with their hospitalized sick child. The first problem that must be faced is renovating the hospitals and providing them with rooms for children and mothers, with sofa beds and other furniture, thereby definitively canceling the wards. There is no doubt that allowing the mother to stay with her child is the best way to overcome resistance and to make the unnatural separation of the sick child from his/her mother and the rest of the family less traumatic at an especially fragile time for both. Therapeutic alliance is the best way to help the sick child and his/her families cope with hospital life [6]. Direct involvement of the mothers has proved to be, as expected, a real advantage. It has been shown that the disease course is better and shorter when direct assistance is provided by the mother, as well as when she is present during the visit, in the medical room, in surgical pre-anesthesia and in the awakening hall.

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