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The Vulnerability of Children and Adolescents in Severe Diseases: Some Reflections [1]

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Abstract: Pediatric psychology action in the pediatric clinical-surgical high complexity unit has become increasingly necessary. It allows for the possibility of integrating complex pediatric clinical-surgical operations by reducing painful effects on the emotional world of children and adolescents. The pediatric psychologist in a pediatric unit continuously oversees children and adolescents (C/A) throughout the entire therapeutic process, extending activity to parents and healthcare personnel. In ill children and adolescents, physical pain and psychological suffering follow, with minimal temporary variations, the same clinical path with continuous changes which put a strain on the ability of children, adolescents, parents and healthcare staff to cope with stress.

Keywords: pediatric psychology; the vulnerability of ill children and adolescents; communication (diagnosis; ill child/adolescent; parents; healthcare personnel); stress

1. Vulnerability

The vulnerability of children and adolescents (C/A) with severe chronic diseases is an aspect that is still insufficiently considered.

The first formulation of the Vulnerable Child Syndrome (VCS) dates back to Green and Sonnet (1964): it represented a different way of observing the negative consequences of an evident psychological fragility of parents when it came to a chronic illness of their son/daughter.

They sensed how important it was to consider the psychological fragility of parents in the face of a son/daughter's illness perceived as dangerous to his/her development; they had detected in the observed children a common behavioral phenotype, characterized by separation anxiety, somatic pain, school difficulties, hyperactivity, and other predominantly externalizing behaviors. (Green, Solnit. 1964) [3].

Over time, the existence of *multiple vulnerabilities* has been understood; as a matter of fact, they involve: a) the different experiences of parents in front of their child's illness; b) the experiences of the ill child, which are not always communicated; c) his or her illness clinical history; d) the support of the extended family (grandparents above all); e) the presence/absence of a community of reference. (Boyce. 1992; Thomasgard, Metz. 1999) [4].

Gleason (2004) had observed that both children and adolescents were perceived by their parents as still particularly fragile despite having overcome the critical stage, with a marked improvement in their clinical condition. (Gleason, Evans. 2004) [5].

The perception of an ill child's fragility may persist beyond his/her actual health conditions; experiences related to the clinical history of the disease persist for a long time in the minds of parents, who are not very receptive to predominantly rational reassurances.

2. Communication of the Diagnosis

Since the very communication of the diagnosis, a child's illness initiates psychological suffering of the family that can persist for a long time and that involves, with varying intensity, the sick C/A and the entire family unit.

The *first diagnostic information* can be subdivided into two parts: in the first one, anxiety and anguish over a "*verdict*" are intensely present, accompanied by thousands of unanswered questions.

This is followed by complex communication, crowded with a thousand thoughts, with "*many unspoken words*"; sometimes, the informing health care provider may be tempted to fill a highly anxiogenic space with a myriad of details and statistical data: the parents, in turn, are confronted with *a mind space of their own* that is so disturbed that it reduces their ability to "*really realize*." [6].

Parents have difficulty coping with a "*waterfall*" of information": they are already under "*an emotional tsunami*" [7].

A variable that is scarcely considered is the intensity of the parent's *self-perceived* psychological distress; indeed, it was found that parents who had had more support at the time of diagnosis were those who showed a lower level of self-perceived distress. (Hoekstra-Weebers et al. 2001) [8].

It is possible that by the time the diagnosis is communicated, some couples may have already been in an affective-relational crisis for some time; others manage to support each other, sharing the difficulties of a *new role*. Regardless of their affective-relational situation, there is a need for parents to share *educational consistency*; siblings are also no less confused and troubled.

Early psychological support to the family can have a kind of halo effect that manages to maintain a certain positivity over time.

3. Parents, Parenting

A child's illness forces parents to deal with countless unknown and complex situations: this is confirmed by the narration of their experiences, fears, impulses, as well as the deep sense of loneliness and inadequacy suffered by many.

Clinical experience has shown how some mothers tended to suddenly accentuate behaviors of both approaching and affective detachment from their ill child, often camouflaged by overprotective behaviors which a considerable state of anxiety was associated with; not infrequently, this determined in their son/daughter a considerable level of affective-relational disorder with abandonment-like reactions. (Biondi. 2020) [9].

Some of them justified such behaviors by the persistence of a deep sense of loneliness: "*I don't know, but I feel that I am not capable ... it's as if I were superimposed on my child ... I am confused ... I sense that everything is within a situation of love and anger ... they are mixed together ... and I feel confused, inadequate ...I don't understand anything anymore.*" [10].

In caring for an ill C/A, parenting represents a complex affective-educational process ... parents act in a continuous process of adaptation confronted, overlaid with their different backgrounds, personalities, experiences.

Guidelines should include support protocols for parents that are truly actionable; many of them suffer a strong sense of inadequacy: the complex, prolonged clinical journey goes hand in hand with the affective-educational one; it engages the entire family system forced to cope with unpredictable and painful changes.

4. Siblings

Especially in the early period, it is very difficult for parents to *limit and hide* their emotions from the other children, and to keep *"a mental and attention balance"* that includes equally concern for their child diagnosed with *"a terrible illness"* and his/her siblings. *"We were trying to share tasks, but the level of anxiety was too high...we were inevitably inattentive towards other children's questions"* [11].

Siblings promptly sense changes in the family atmosphere; they are unlikely to calm down when faced with the unsaid, or with generic, rapid, superficial reassurances which often raise a sense of confusion and concern, associated with the discomfort of feeling little considered by their parents. (Goudie A et al. 2013) [12].

The illness of a brother/sister is an experience that is pervaded by an intense feeling of loss, which often activates a personal perception of psychological fragility; in some cases, a marked reduction of psychosocial skills can be observed with clear signs of *psychological suffering-discomfort*. (Murray. 1999; Hui-Chuan et al. 2016) [13].

It is not rare for parents to activate a *protective silence* with siblings: it favors the establishment of anxiety-provoking fantasies, which are difficult to verbalize and which are extremely complex to free oneself from; over time, siblings can develop a sense of *mental crowding* (Biondi et al. 1990)[14], which can alter their psychological balance, driving concentration difficulties, poor academic performance, a tendency to isolate, aggressive behavior - that is not always contained - towards themselves or others.

In a nutshell, siblings of a C/A with a severe and complex illness live in great relational and role confusion in their family life. Early psychological support for parents would allow them to evaluate their siblings' needs and provide suitable resources for a less troublesome adaptation.

5. Hospitalization

Pei-Fan Mu et al. (2015) highlighted that the intensity of stress of a family with a minor with cancer continues during the year following the diagnosis with unstable developments; it is often influenced by the original contrast strategies that the family system activates to avoid being overwhelmed and which do not always prove to be effective [15].

Faced with a serious illness of a son/daughter, parents are forced to compare their resources with the multiple requests that, directly and indirectly, are continuously made by the hospital system.

Faced with prolonged hospitalization and treatment timing, parents showed greater problems in having to renew their adaptation skills, with a consequent rise in stress levels; those who encountered greater obstacles while dealing with such different contexts, unknown in terms of organization and languages, appeared more exposed. Such dynamics inevitably involved healthcare personnel who were not always able to limit parents' tensions.

The *continuous and frequent* changes in the therapeutic process, sometimes so unpredictable and sudden, determine an alteration of emotional-relational conditions that are not easy for parents to manage, raising conflicts that are not always verbalized, feelings of guilt, and confusion in finding one's own space: Furthermore, the child's illness is overloaded by family, professional and social roles: it is very complex to be able to reorder without damaging the *relational and mental space* to be dedicated to the ill child and his brothers/sisters.

It has been observed that parents who already present significant emotional fragility tend to have a higher perception of stress: they require special attention on behalf of healthcare personnel; over time, it is possible for them to encounter greater difficulty in being cooperative, with the actual risk of suffering from the effects of Traumatic Stress Disorder (TSD). The following conditions have been reported as the most frequent ones following the appearance of Post Traumatic Stress Disorder (PTSD): a) poor social support, b) negative experiences due to clinical-invasive procedures, c) an unfavorable belief about the progress of the C/A's illness and/or the proposed treatments. (Franck et al. 2015) [16].

6. Silence in Communication with the Ill C/A

It is not easy for the ill C/A to communicate with the *Department system* and its subsystems: he/she is forced to learn the countless, diverse, often incomprehensible, languages (communicative and meta-communicative) used by the individual operator in a *set* of codes that are not easily decipherable.

In the relationship with the ill C/A, many healthcare workers prefer to fill in the *communication spaces* using a large number of words: these often have the function of avoiding to answer questions which are difficult and painful to reply to; on the other hand, experience has confirmed how important the role of *silence* is in communication. The C/A *needs to feel* someone close by, but *in silence*: the desire is to be listened to in a highly communicative silence. It is not easy to communicate with the *different silences* of the ill C/A if not by trying to listen to them: it is a listening process composed of attentive, profound glances, a light tactile relationship, respectful of his/her physical and emotional space.

7. A Few Procedures to Combat Stress

Although briefly, some procedures are indicated and, in clinical experience, they have proven to be particularly effective in combating the stress burden of the ill sick C/A and parents, helping to reduce the Vulnerable Child Syndrome risk.

First, it is necessary to consider parental stress, especially if we observe the family as an interactive system that shares stories and emotions.

The quality of support provided by medical personnel and the psychological characteristics of the C/A and parents both play an important role in stress management; no less important is the quality of the emotional-relational relationships present in the family system prior to the onset of the disease.

It is important to be able to significantly contain the sense of insecurity in parents, reducing the perception of a highly stressful environment; in particular: a) collaboration with healthcare professionals, b) welcoming their concerns, c) consideration, not just formal, of their role and responsibilities, d) informing and clarifying the clinical procedures which, over time, shall be adopted.

A good relationship with professionals can contribute to a less stressful hospitalization experienced, both for the C/A and for the entire family unit with numerous positive effects on the quality of communication and hospital stay.

Nurses play an important role in the entire treatment process (often prolonged due to the chronicity and complexity of the diseases treated); the increasing number of admissions of C/A coming from outside the region or from foreign countries has enhanced their further role as *cultural mediators* set in the difficult relationships among parents, C/A and staff.

The physician has a therapeutic power that goes beyond drugs (Jensen et al. 2013); [17] the doctor-C/A relationship is a delicate one; the doctor's tendency to favor *speaking over listening* can be a source of mutual misunderstandings and conflicts that undermine the quality of the relationship and, in turn, the therapeutic value of the relationship itself.

In numerous onco-hematology departments, psychological support actions have been tested on parents with difficult stress control to reduce the perception of stress, and to reduce and prevent the development and/or persistence of symptoms of possible post-stress traumatic. (Wellish et al. 1978; Minuchin, Fishman. 1981; Manne, 2021) [18].

Still today, the need for psychological support for the medical and nursing staff is scarcely considered. (Lam et al. 2006) [19].

Experience gained in multiple decades of activity in an Onco-hematology department has highlighted the validity of Balint groups in pediatric disease departments featuring high clinical-emotional complexity for both physicians and nurses [20].

A greater presence and integration of the pediatric psychologist in the staff of pediatric departments will ease the implementation of a truly holistic action, capable of effectively responding to the psycho-physical needs of ill C/A and their parents, as well as those of the healthcare personnel.

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