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## **SUFFERING IN CHRONICALLY ILL CHILDREN IN THE CONTEXT OF PSYCHOLOGICAL INTERACTIONS SUPPORTING THEIR FAMILIES**

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**suffering child**  
**chronic illness of a child**  
**family**

**Summary:** This article, taking into account the contemporary achievements in the area of the developmental psychology and physiological psychology, contains an attempt to outline the differences concerning a child's experience of distress in general and of physical pain. The pain is interpreted as a specific somatic sensation of high intensity, felt as a consequence of disorders resulting from a disease or body dysfunction. Suffering means an intense and emotionally upsetting feeling of undefined character, having specific physiological correlates. A child, suffering from a chronic illness or a visible and permanent disability may experience various kinds of sense of loss, which in many cases means an experience of a great despair felt by the child and its family. The paper shows that a child's suffering, consistently with the stage of its development, often co-incides with: - noticeable disturbance in the cognitive and socio-emotional development, caused by incomprehensible and upsetting stimuli, - disorder of identity development and personal integrity, - gradual loss of hope that fitness can be preserved, - relative disorganisation of activity and functioning in a situation of stimulation caused by pain and loss of the sense of safety. The forms of reality perception referred to in the paper are associated with certain attitudes, beliefs, emotions and reactions in suffering children, which are the consequences of the experience of loss directly affecting both the child and the entire family system. The conclusion of the article constitutes an attempt to answer the question: what message and how should be conveyed to the children when they experience suffering, and how, using the organizational potential available, could an effective support be provided?

### **Introduction**

Child suffering is an existential paradox of its own, considered in individual and social contexts. The experience of suffering surpasses the borders of adult world, touching people who, from the point of view of age, are on the threshold of developmental potential, and at the same time, it deprives their parents of the opportunity and, occasionally, hope for protecting their offspring from hardships. Developmental psychology [1] emphasises the great potential of a child. However, in relation to children suffering from illness or disability, it seems to be treated not as much as a kind of an asset or a special advantage, which could be profitably used in work with them, but rather as a sign of therapeutic and compensative prospects.

Many researchers interested in the problem of work with the terminally ill, see a unique character of the bond between the terminally ill and their family and therapists. The unique character of this relation results from the fact that, among other things, treatment is generally undertaken to overcome an illness or a disability.

In the analysed context, the aim of care provided for the ill is to make their remaining time on earth as happy as possible, and keeping patients in a state of psychophysical well-being and in the atmosphere of dignity.

Problems of suffering and death, as few others, are subject to cultural and civilizational changes [2]. The issue of characterisation of child suffering is dependent on the description of culture in which we are raised, inter alia, as well as our responsibility for the ill, which is a cultural consequence, and also personal experience connected with supporting a child in pain. These experiences bear a special meaning in terms of planning and organising support for families touched by a chronic illness of a child.

In psychological perspective of ill person and their closest relatives, words are of lesser importance. What matters are the facts and genuine presence of supportive people.

Asking what the difference between suffering of a child and suffering of an adult person is, many therapeutic approaches assume an incorrect conviction that the child is a miniature of an adult. However, from psychological perspective, the child does not resemble an adult person in cognitive, emotional spheres and the social facet.

### **1. Child development and undergoing changes as a result of a chronic illness**

Considering child suffering in an individual context, attention is drawn to the fact that in various moments in life, depending on the level of cognitive development, children can perceive information concerning their condition differently as well as what is happening with their body and what is accessible to them in direct, subject experience.

The way child perceives medical procedures is conspicuously linked with the process of cognitive development. Still, even in this, there is a certain paradox. The common knowledge has it that cognitive development precedes emotional advancement, whereas it tends to be contrary in case of terminally ill, suffering children [1]. The emotions experienced by children shape their ability to perceive a social situation (also the one directly connected with the illness from which one is suffering). This phenomenon, considered from a systemic point of view, is particularly visible in the social dimension when the influence of parents, their understanding of the condition of a child, and the degree in which the child experiences the consequences of an illness can significantly affect the quality of the perceived developmental changes.

The diversity of human brain functions results from a complex interaction between genetic potential and individual experiences of a human being which are appropriately situated in time [3]. The areas of the nervous system upon which the cognitive, emotional, social and physiological functioning of a human being depends are developed in childhood. Thus the main role in shaping functional efficacy is served by the emotions of a child. The lack of indispensable explorative experiences in chronically ill children results in the fact that their nervous system does not develop in an optimal way [4].

A. Brzezińska [5] in her works, basing on the *concept of unpunctual life events* which are the factors disorganising the process of child development, indicates that illness and suffering lead to a disruption in the process of shaping identity. This prevents from satisfying the need of a meaningful life.

In accordance with the assumptions of the concept in quote, everyone is placed in two contexts in which their development progresses from the moment of birth: biological (i.e. belonging to a specific age group) and social (generational).

Thinking about basic developmental characteristics describing child experience in various periods, four basic stages can be distinguished. These stages seem crucial in the process of preparing a child to learn about her or his health condition. Analysing hospice care for children, not only children suffering from cancerous diseases are considered. In case of youngsters, this kind of care concerns persons with progressing developmental disorders leading to disability more frequently. While pondering over the criteria of how children understand the information regarding their health, we usually focus on their age, whereas it would be more appropriate to relate to the scope of their cognitive, emotional and social skills, rightly adjusting the content of the medical message to their competence. Assuming Piaget's view of the cognitive development [6] as well as conclusions reached by other researchers [3-5], in case of children whose mental development is situated within the sensorimotor stage, i.e. characteristic of the majority of healthy children circa 2 years old, who at this point learn the most important things through their senses. If children feel pain, this sensation can entirely disrupt their experience, determine their needs and perception of the world. Pain also affects the cognitive advancement of a child in the most evident way, inhibiting the development of communication and complicating the possibility of exploring immediate environment [7-9] among other things. When children feel physical pain, they might have difficulties with naming and communicating the emotions they are experiencing [7]. The lack of expertise in the characteristics of child functioning during the sensorimotor stage leads to creation of many myths entailing an incorrect understanding of child development, especially, the way children feel pain, in not so distant past. It was maintained that children, supposedly, endured pain better than adults. It was also believed that due to immaturity of their nervous system they did not feel pain at all, or at least when they were asleep. This view was questioned by research [8] on infants who underwent surgical procedures with local anaesthesia or lack of anaesthesia. An acute stress reaction was observed in these children was connected to the raise in the concentration of catecholamines, glucagon, corticosteroids, growth hormone as well as ketone bodies and lactates in blood, with the simultaneous drop of concentration of insulin with subsequent hyperglycaemia. At the same time, infants who were subject to general anaesthesia were reported to suffer from fewer complications and the time of their recovery was shorter [8]. Another fundamental issue is free movement, to which Piaget [6] attributes a decisive role in sensorimotor stage, associating it with optimal intellectual development. Every limitation to the possibility of physical manipulation of objects or reaching them as well as reduced mobility pose a threat to correct development and

optimal functioning of children [10, 11]. In the sensorimotor stage it is important that the parents watch their children and accurately identify symptoms displayed by them. Conducting research with psycho-educational service in University Children's Hospital of Cracow, Prokocim [12] we were faced with interesting observation made by parents. They noticed that in spite of invasive procedures related to therapy, children residing in hospital remained in a relatively good emotional state. However, when they returned home from hospital, despite an objectively formulated diagnosis of stable health condition while in hospital, they started to display symptoms of worse state of mind. After a more in-depth analysis, the explanation for this situation is quite simple. Excluding medical reasons, it seems that a 2-year-old child has quite correctly identified meaningful people in her or his life. In accordance with the concepts of systems psychology and the possibilities outlined by cognitive development, the child abreacts emotional tension she or he has been experiencing, and manifests provocative behaviour towards people who she or he finds important. In the aforementioned circumstances, one could congratulate the parents on the cognitive capabilities of their child as, in spite of numerous ailments with which the child has been afflicted, she or he has been able to distinguish meaningful individuals from among many people from her or his environment.

In the case of slightly older children, i.e. in the preoperational stage (2-6 years), following Piaget's theory, there is a considerable danger that by focussing on the occurrences from direct experience, children will associate the causality of their own illness, e.g. by feeling guilt [9]. It may be associated with specific circumstances of their disease, e.g. a complicated family situation. When children experience guilt directed towards their social environment, it may inhibit the treatment process.

In later stages of child's life, communication becomes relatively easier. Older children have wider experience and are willing to engage in therapy, as they understand the context of what is happening. Children in the concrete operational stage, i.e. between 6 and 12 years old identify threats as consequences of something very concrete and tangible, e.g. bacteria, incorrect physique or body functioning etc.

Only when children are about 12 years old (according to Piaget's typology it is the formal operational stage), they become partners capable of understanding therapeutic context. Also at this stage, children are more willing to participate in conversations with doctors concerning their condition and planned form of treatment [5-7]. Following Aldridge's [13] opinion, parents tend to justify their hope only when the child is not aware of the whole truth. Whereas Obuchowska [14], challenging this view, emphasises the fact the way the young patient communicates with medical personnel should serve as an equally important part of the healing process as administering medication or complying with the prescribed treatment, as it allows for seeing sense in pain as well as other unpleasant ailments and experiences. Enabling children to have honest communication (to the extent to which they are capable) with medical personnel teaches them to name and interpret their own physical and emotional states and search for support in difficult situations, making them more independent in the broader perspective [14]. And so does the way parents communicate with the child, which is an expression of their knowledge of the health condition of their child. What might help in creating

an impression of effectuation is allowing children to make decisions related to practical aspects of therapy, e.g. being able to choose on which arm to perform venipuncture or a vessel in which they will be given medications etc. There is a chance that children will not then experience their disease through the prism of emotions expressed by the parents and their reaction. Many researchers [15, 16], taking cognitive capabilities characteristic of the developmental stage of children into consideration, believe that young patients may absorb the experience of both their own suffering, which is the consequence of the illness, as well as suffering of other persons, e.g. parents.

## **2. Child development and the possibility to provide child with support in the struggle with suffering inflicted by illness and therapy**

Having an extensive knowledge on child development and, at the same time noticing, a deficiency of practical skills in terms of providing children with help, we are often faced with lack of clear reference to the relationship between the suffering children and their family. To provide a child with effective support in suffering it is crucial to notice that the child displays some competence. It applies first and foremost to the capability of a sick child to build an emotional relationship with a parent, which is based on a bond. Whereas the condition of developing this competence, labelled as emotional self-control, in a child is effective communication with surrounding environment, which enables to regulate the emotions she or he experiences correctly. Acquisition of self-control develops a sense of adaptability in a child, which is a prerequisite for feeling safe and minimisation of the experience of loss.

The presented model of interactions, put forward by the Thompson's team [17–19], is included in ecological systems theories. Chronic illness or disability are often formulated in this convention as a potential stress factor, which influences both the child and the family. This model comprises a specific categorisation of factors affecting child's adaptability. They are described as basic factors (traits of the very sickness as well as cultural and demographic aspects) and mediating factors (mother and child's ability to adapt). In line with the assumptions of the model in quote, the course of adaptation of a sick child is, therefore, modified by both intra psychic factors (e.g. cognitive competences, self-esteem, locus of control, strategies of coping with stress) as well as environmental ones (e.g. functioning of a family). Empirical studies verifying the adequacy of this model were conducted in reference to groups of children raised in various cultures, suffering from various disorders e.g. cystic fibrosis [19], spina bifida [18] and haemolytic anaemia [17, 18]. The studies have shown that the explanation of conditioning of the correct or distorted adaptation to an illness is possible owing to transactional approach. The assumed perspective makes it possible to notice developmental factors in the process of minimising suffering and take into consideration various theoretical models of child chronic illness and the process of adaptation to its symptoms. Thompson's assumptions have been also applied in own research conducted in relation to various groups of chronically ill children and youth with disabilities:

neurological disorders [20], adolescent idiopathic scoliosis [21], cerebral palsy [22] and of other etiology [23]. The conducted research [12, 21, 23] shows suffering children attribute a special meaning to their experiences, as they denote the risk of remembering the details relating to especially unpleasant medical procedures and sensitiveness to negative aspects of their functioning in the social context. In case of suffering children under treatment, memory turns out to be an underestimated phenomenon, especially from a long-term perspective.

A child who, as it has been mentioned before, is not a miniature of an adult, perceives all signals coming from the environment as more emotionally threatening and painful. Illness and suffering resulting from it lead to changing living conditions, possibilities, perception of one's self and views of the future. Also in this context, serious somatic disorder or a disability that appear in adolescence pose many emotional problems.

As Kowalik [24] notices, following the concept of Kohut, to which he refers, the basis of the correct development is what we call healthy narcissism, namely, a conviction of one's worth – an experience of disability or other limitations resulting from a chronic disease, and suffering, destabilise self-acceptance. An objective awareness and subjective experience of loss of some assets negatively affect the choice of one's life objectives, intensifying the isolation of chronically ill children or stigmatising them in a peer group.

Research [13, 25, 26] reveals that on numerous occasions a serious illness of a child results in that the parents disengage with their acquaintances, as the latter believe that speaking about developmental problems of healthy children and personal experience relating to their standard advancement might be perceived as embarrassing, tactless or even unfeeling. Often, what is emphasised in the subject literature mentioned in the text [26], medical personnel, who takes care of the young patients has problems with accepting unfair and not easy, or logical interpretations of why children suffer. For that reason, in order to deal with such difficulties, some people employ coping strategies, which make patient's parents perceive them as cold and depersonalising.

It is worth noticing that the social sphere not only specifies the situation of treating children, but also does it affect the way in which they experience stress induced by the illness, as according to the researchers [27] it is determined by the social environment. Very often, when parents are faced with an unfavourable diagnosis, bound to a perspective of subjecting their child to unpleasant sensations and a negative prognosis, they do not assume the role of partners in caring or medical environment, but they want to protect their child at all costs [12]. In the systemic or social context, this phenomenon is relatively easy to explain. By personal suffering and sickness, the child is as if snatched away from the arms of loving parents. Parents, overcome by fear, perceive the situation of the child as if their offspring were deprived of the feeling of being cared for and safety, which is granted by them. Therefore, the parents often subconsciously and naturally assume the new role of unconditional protectors of their child. Sometimes they even ignore real psychological needs of a child and doctors' recommendations.

Children assume the way of interpreting their disease and its emotional context from the environment to which they belong, and the organisation in which they are hospitalised also constitutes a component of a broadly understood social ecosystem [23].

The majority of children positively react to stable, loving care, and the adequate bond between parents and children, as well as optimistic attitude, the ability to enter into task-oriented relations with the medical personnel, and a cheerful mood, have a positive effect on the efficacy of treatment [26, 27].

There are many strategies of coping with stress. Psychotherapeutic influences connected with relieving anxiety have been mentioned among other things. They gain even greater importance in case of children than adults, therefore, especially in the two first stages of cognitive development some of its aspects occur only based on the external signals (so, if the child does not recognise any danger, the pain situation is under control etc., then the stressful event may originate only in the immediate environment of a child). However, most often the source of such events is the family system. Danger is sometimes induced by the parents, unable to deal with the disease, suffering or child's disability. Therefore, it seems most valid to place among the five strategies of mental health promotion among physically impaired children, as Patterson and Geber [28] did, a strategy of developing searching skills and the ability to use social support. It would be great if the parents also possessed this skill. In this context Pilecka [29] emphasises that "promotion of mental health in chronically ill children signifies expressing and satisfying the needs of other family members, which also [...] requires multi-systemic approach".

According to contemporary psychology [30], which broadens the results of Suzanne Anthony and Maria Nagy's [after: 16] analyses and research on using stages of cognitive development of children and young people in making them understand their suffering better, each child is able to absorb the experience connected with their own suffering and pain felt by others in the boundaries delineated by their own developmental stage.

The quality of life of an ill child rests also on the individualised perception of her or his own disease. It is obvious that it depends on the amount of information regarding the illness and its treatment [21] which is passed to the child, but also on the functioning of child's environment (especially closest relatives). Upon Bowlby's [1] theory of attachment, there is an indirect connection between the way mother copes with stress and eliminating the risk of developing the mechanism of learned helplessness by a child. This in turn affects the improvement of child's emotional functioning and more positive perception of the environment [1]. Contrary to what it looks like in case of child's image of illness, rarely can one observe what we call therapeutic pessimism (perceived as a generalised conviction of a negative prognosis). And even if it occurs, it is mostly the result of direct contact with suffering and death of other patients in the ward [31].

An unceasing thought, called rumination, which focuses on all aspects of the illness, and especially the limitations it entails, is a dangerous psychological mechanism which can occur in a child suffering from a chronic somatic disease. The basis of this mechanism is what we call a vicious circle: thinking about sickness

leads to a deterioration of well-being of an individual, causes stress and lowers self-esteem, which in turn affects the psycho-physical functioning of a person [31]. However, research conducted by Ogińska-Bulik [32] indicates that in adults suffering from oncologic diseases ruminations appearing shortly after the diagnosis, are favourably correlated with the level of post-traumatic growth of these persons. Therefore, it would be interesting to investigate whether a similar correlation exists in children and adolescents.

A model of tanato-pedagogical skills of a therapist, put forward by Nowicka and Bąbka [33] emphasises the need of complex support provided for chronically ill children at each stage of suffering. At the basis of this model the authors place interpretative and executive skills of specialists. The first are related to the ability to adequately interpret the needs and the state of the child which is cared for. The second, on the other hand, correspond to the technical competence of therapists and are decisive factors in terms of the elasticity and effectiveness of their work. The authors [33] stipulate distinguishing tanato-pedagogy as a separate course in university education, which allows to express reasonable hope for intensifying aspirations and activity of specialists from various realms, leading to the creation an interdisciplinary model of support of the entire ecosystem of an ill child at every stage of the disease and, if necessary, also after child's death.

### **3. Selected ways of providing a suffering child with support in family environment. How to talk with children about suffering?**

At the moment in Poland, having identified and used the offer of various systems accurately (especially education and health care), it is possible to plan a relatively satisfactory and complementing care for an ill, suffering child. It relates to the execution of legislative acts, especially those from the realm of national education department (e.g. on October 30, 2013r. a regulation of the Minister of National Education as of October 11, 2013 (Journal of Laws of the Republic of Poland, item 1257) on organisation of early assistance of children development [34], came into force allowing the child to have a what we call an early intervention and early support for the child development, which is realised from the moment the disability has been diagnosed or the threat of disability till the beginning of school education).

People supporting children achieve the most favourable results when the support they provide is adjusted to the cognitive (informing on the course of therapy), instrumental (regarding the everyday treatment and educational practice) as well as physical (the reduction of somatic pain) needs of children. Therapy is supported also in the area of realisation of other needs of a child: emotional (alleviation of anxiety, optimisation of mood), social (satisfactory interpersonal relations) and existential (including cultural, spiritual and religious facts in therapy) [16]. So characterised, multifaceted therapeutic help allows the suffering children to accept the worth of life as well as the fact that the situation in which anxiety and grief resulting from the sustained losses and the ability to cope with the adversities are naturally interconnected. It acquires a motivating significance in the process of medical and psychological therapy. What is also helpful is the attention paid to analysing the questions formulated by children and resolving their uncertainties. On the one

hand, the questions determine the scope of the information they require, and on the other, they often suggest the way and circumstances in which children would like to talk about their sickness and the suffering it entails. Leaving children's suffering unsaid deprives them of the possibility to share their feelings and results in increasing anxiety and intensification of loneliness. Young children do not possess the skills enabling them to describe feelings, and for that reason they need the help of adults to verbalise their emotional states. Hence, irrespective of personal intentions and beliefs, often unintentionally, we shape our emotions and feeling of children. Experiencing e.g. anxiety, worry and manifesting one's horror, we are intensifying the fear reaction in a child.

Paradoxically, it is believed that talking about the suffering experienced by children will be harmful for them, and for that reason we are "protecting" them from their problem. However, the children learn about suffering despite our worries and it is out of our control. It would be preferable, then, to explain the problem worrying the child, before an incorrect interpretation of their experience is made, the one inspired by the aforementioned sources of non-adaptive nature. It is recommendable to speak with children about the problem of suffering. By doing so they are given a possibility to understand the physical dimension of symptoms of suffering and treat it as something natural, though painful. In this way the child is relieved from thinking about suffering in a magical, distorted way. At this point it is worth alluding to the nature of the world: nature allows us to place pain and suffering in the right perspective and provides us with an opportunity to tell the child for the first time that e.g. pain is an inevitable part of life of every creature. Noticing that the child is satisfied with such a short answer (e.g. when the child calmly continues to play), it means that one should confine oneself to what has already been said. However, when one notices that the child is embarrassed, terrified or falls into tears, it would be necessary to provide her or him with more accurate, in-depth information which would restore the sense of safety.

In the therapeutic proceedings some rules have been formulated, which can prove helpful in the process of supporting ill persons and their closest relatives. The first one applies to the degree of sensitivity of ill children towards all information connected with their dysfunction, which may arouse anxiety, cause harm or distress. It is advisable to familiarise oneself with the individual life story and medical data of particular children, and especially their expectations towards the future, their plans and dreams. Knowing the way in which children interpret the experiences in relation to the world and their closest relatives is also valuable.

The second rule deals with learning about child's illness, the limitations and threats it entails as well as its biological and medical grounds, the symptoms of the disease and its biological consequences. This knowledge allows for preparation of the sick child for potential difficulties which may occur during the course of illness.

The third rule applies to limiting fear of the disease and its consequences in the life of the young patient. It means that it is necessary (which will sound paradoxical) to demonstrate the smallest success in the battle

with the disease or losing one's agility, as well as to develop the sense of control over the course of illness. This positively affects creation of the atmosphere of security for a sick child, boosting the sense of mental well-being.

The course of activities connected with the struggle of ill children with the disease is delineated by the degree of their social and personality maturity, sensitivity and what their knowledge of the disease is. Irrespective of the psycho-physical state of children and the stage of advancement of the disease, they always require complex support of the environment, which would encompass all aspects delineating the current situation and would be directed more towards the individualised needs of the child.

The most valuable help in child's struggle with suffering and sickness is adequate support of the closest relatives, as it strengthens and reconstructs child's shaken feeling of safety and has a significant meaning in counteracting child's feeling of loneliness and long-term sequelae of the disease.

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