

# CHRONIC ILLNESS IN CHILDHOOD: PSYCHOSOCIAL ADAPTATION AND NURSING SUPPORT FOR THE CHILD AND FAMILY

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**Abstract:** Chronic illness in childhood is discussed with particular reference to the nurses' role. Both the child and the parents need to adapt to the situation from its early stages. The nursing personnel should be able to help and alleviate not only the physical problems, but also the psychological consequences to the child, as well as reducing the parents' stress and their possibly overprotective attitude towards the child. Also, the child should not be treated with derision or his condition down rated, especially when the disorder is hereditary. The role of the health care team is at its most beneficial when it can identify stress factors and help the child and family adopt constructive

ways and methods to face them. The most suitable phase for this psychological and nursing intervention is during the initial stages as soon as possible after the diagnosis. Without nursing support, a family can find itself in crisis and its members may try inappropriate methods of coping which can be detrimental to the short or long-term adaptation to the child's illness. However, even if an early phase nursing intervention is missed, later support can still be of enormous value.

**Keywords:** chronic illness, nursing intervention, psychological support of the sick child

## INTRODUCTION

Chronic illnesses are defined as physical or mental conditions, that affect the daily functioning of individuals for intervals longer than three months a year, or for a duration of hospitalisation longer than one month. Chronic illnesses include: cerebral palsy, diabetes, chronic renal insufficiency, epilepsy, Down's syndrome and other inherited chromosomal anomalies, cystic fibrosis, heart conditions, cancer, juvenile arthritis, asthma, dermatitis (including severe eczema and psoriasis), leukaemia and various types of anaemia. Further, physical handicaps include: deformities, amputations, burns and other severe dermal damage. All of these are known to affect the psychological and physical development of the child. Consequently, a child with a chronic illness is one who is rendered unable to participate in activities considered normal for his age.<sup>1,2</sup>

The statistical data concerning the prevalence of chronic diseases in children are of great concern. Epidemiological studies show that roughly one in ten children under the age of 15 suffers from a chronic disease. Other, epidemiologic studies estimate that one third of children under 18 years of age are suffering from one or more chronic disorders or diseases.<sup>3,4,5</sup> In addition, there is an increased prevalence of learning and speech difficulties, sensory dysfunctions, mental handicaps and behavioural problems. These conditions can be diagnosed and assessed with the use of psychometric tools which are constantly improving.<sup>6,7</sup>

## Effects of chronic illness on the child

For the child and the family, the diagnosis of chronic disease in childhood can cause mental shock, stress, sentiments of anger, sorrow, and increased intensity in their interpersonal relationships. Particularly distressing, however, is the diagnosis of disease for a child who was previously healthy.<sup>8</sup> Chronic illness is a very difficult challenge for a child, who may often be afraid of both the illness and the laborious processes of treatment.<sup>9</sup> At first, children do not usually comprehend the complexities of diagnosis and treatment and confusion arises as they try to cope with the illness and medical interventions. A child with a chronic disease can not always follow the treatment easily, so more help and support is needed from the family in comparison with an adult. To make matters worse, a child may experience unjustifiable guilt due to a belief that the suffering experienced is a punishment for either his or his parents' past sins. In many cases children view their situation as permanent and may fear

that it will become progressively worse. In this case panic will arise influencing their ability to deal with the symptoms and to learn ways of coping on a physical and psychological level. An insecure child can increase parental stress, which in turn can further increase the stress of the child and may even involve behavioural disturbances.<sup>10</sup>

Other psycho-social reactions of children towards chronic illness, (besides regarding the illness as a punishment), include fear of rejection, low self-esteem, insecurity related to limited educational prospects, fear of restrictions inflicted by the situation and anxiety about how others will react to the illness, especially the reactions of peer groups.<sup>11</sup>

The way a child reacts and confronts chronic illness varies depending on personality traits, age, social attitudes, the child's relationship with the parents and other factors. Psychological states certainly influence the course of the illness and admitting a child to hospital can be a potentially traumatic experience.<sup>12</sup>

The majority of these children have an intense wish for a fast recovery or to learn techniques which can ease their condition. These can be reinforced if the child is prepared to comply with the treatment. For this to happen, the support of the health professionals is vital, so the child can cope with an initial prolonged hospitalisation and yet attain some degree of independence. A sense of capability highlights his newly acquired self-confidence and prepares him to face future difficulties.<sup>13</sup>

Although symptoms vary from one disease to another, pain and despair are universally common. Further trauma can arise from frequent hospitalisations and painful treatments. The social rejection of peers can be intense and can often undermine the child's drive for achievement.

The restrictions the child faces due to illness, may lead to feelings of inadequacy believing that he is unacceptably different from the others. For example, the child with a chronic disease, such as thalassaemia or diabetes mellitus may find that repeated medical examinations, a dietetic regimen or other restrictions, highlight the differences rather than the similarities to his peers. Without correct nursing directives, there can be an increased dependence on the parents or other care givers, often resulting in a lack of personal initiative to take control of the disorder. This, in turn, can lead to exclusion from social activities, increased distress and parental overprotection. Unfortunately, some children may become over-demanding and quick-tempered, to rebel against their parents in an attempt to gain some degree of independence. This can be particularly noticeable at puberty; a teenage patient suffering from diabetes or a heart condition can swing into anti-social behaviour or, more seriously, denial of the disease with rejection of the medical treatment, including essential diet and exercise programs. For those that have experienced months of immobilisation, the risk of extreme reactions at the termination of intensive therapy has been documented.<sup>14,15</sup>

## **Effects of chronic illness on the family**

It is natural for parents to experience despair and distress on hearing that their child has a serious and chronic illness especially when it is likely to continue for a lifetime. Families show a wide range of reactions and ways of confronting it but as a general rule they are able to cope better where supportive services are provided for them and their child.

Parental identity can be threatened if they feel that they were responsible for giving birth to an unhealthy child or were unable to protect their child from chronic disease or infirmity. In severe cases the family's philosophy on life, values, dreams, expectations and other hopes can be shattered. Under these circumstances, they are confronted with important decisions they must make and radical changes that can further influence even the structure of the family. Some parents, in a desperate effort to manage the situation, focus only on the short-term, coping on a day to day basis with no long-term objectives and struggling to survive in the face of seemingly insurmountable difficulties.<sup>16</sup>

A common characteristic of these families is parental sadness, although the parents do not usually show overt depression and their mood tends to lift with time and at some point resolve. Nevertheless, depression hits back occasionally. It tends to be in acute phases, notably when the parents are conscious of the fact that their child is not reaching important developmental landmarks

or when they see the increasing independence of other children of the same age. Because families experience different degrees of depression, their need for support also varies. There should exist three main sources of support: professional support; family or kinship support and self-help groups.<sup>17</sup>

Health professionals can work directly with parents in order to help alleviate despair and to mobilise outside help from medic, allied health professionals, and social or other support services, where available.

The extended family in Greece often provides a vital source of practical support for the family. In some situations the burden of care can be off-loaded onto a grandparent who may well be in suboptimal health thus placing both the child and the carer at extra risk of further hospitalisation.

For many parents invaluable help comes from contacting other families with a similar problem. Such contacts can be located in self-help organisations or adult groups. Ideal contacts are those that begin with empathy then move forward with suggestions of coping strategies which help both the children and their care givers. Support from self-help organizations can be reciprocal as it helps not only the newly diagnosed child and its family but also the family offering support, as they too may think of new strategies to use with their own child.<sup>18</sup>

Open communication and exchange of ideas are important in the constructive adaptation to chronic illnesses. This does not mean only practical tips about the illness and its treatment, but also the expression and acceptance of new perceptions and sentiments that each member of the family experiences with the changing circumstances during a crisis. When support systems function constructively they guarantee family cohesion and the sharing of tasks in a constructive way so that demands are met realistically without overtaxing one particular individual.<sup>19</sup>

When families and social services have explicit, differentiated but complementary roles and collaborate with each other, they can provide a platform of security, affection in addition to practical suggestions that help the ill child and his siblings to be more mature and empowered in confronting their difficulties. In this supportive environment, all caregivers learn to adjust and communicate more effectively concerning all aspects of the child's condition including, when necessary, facing death.<sup>20</sup>

Unfortunately, some parents may consciously adopt secretive attitudes and deliberately avoid informing their child about his illness, treatment or prognosis. In contrast, there are those who spontaneously encourage an open dialogue discussing all the difficulties as they arise and their possible coping strategies. Unfortunately, some parents and members of the medical and nursing personnel often adopt over-protective attitudes, failing to inform the child why a specific treatment has been prescribed. This is especially likely to occur if the child suffers a life-threatening illness when cooperation is essential. They thus ignore one of his most basic needs, that is, his wish to know what he suffers from and how it might be cured or improved. To complicate the issue, if the child is misinformed or 'left in the dark' he may well be ashamed and decide to keep the existence of his chronic illness to himself, refusing to talk about it. When he is embarrassed over his condition, his shame will increase or decrease depending on the perceptions and attitudes of the family, medical and nursing personnel and the reaction of teachers, friends and schoolmates.<sup>21</sup>

## **Psychological support of the child and family**

Investigative studies show that if children are well prepared and know in advance what paths their disorders might take, and which preventative steps are best to follow, their adaptation or recovery rate is faster. Tactics that decrease stress and encourage the child to cooperate when facing hospitalization are as follows:

- a) previous short informative visits
- b) brief conducted tour of the ward
- c) explanation of the purpose of the medication including the reasons for taking blood
- d) visit to the actual surgical theatre where all the stages of surgery can be explained if surgical intervention is expected.<sup>22, 23</sup>

Preparing the child to face his illness should be positive, evolving to a mature approach to the whole experience, which should result in a boost to his self-esteem. Adaptation to the hospital environment is a basic condition for the smooth development of the physical and mental health of the child. The presence of parents provides reassurance at difficult moments, such as during the first few days in hospital, or the day of surgical intervention or if a painful diagnostic examination is to be conducted. Whether or not a parent should stay overnight in the hospital should be discussed. In the early diagnostic stage, however, overnight stays for the first few days or until the child adapts is strongly recommended. The daily presence of parents is of vital importance not only to the child but to the parents, doctors, nurses and other health care professionals. Their presence cultivates an atmosphere of trust and builds beneficial relationships on all sides. A further psychological advantage for the child is to learn that other adults, apart from his parents, can now help him. Thus, at a later time when the parents are absent, the nursing personnel will more easily play surrogate roles, offering safety and protection.<sup>24,25</sup>

As well as the child, the parents need to be reconciled from early on with the situation. The nursing personnel should be adequately trained to help the parents cope with, not only the physical condition but also the psychological problems of the child. This reduces parental stress and lessens the risk of the parents acquiring overprotective strategies towards the child as they learn to fight sentiments of pity which they may feel. We should not underestimate the importance of giving parents the opportunity to watch, participate, learn simple coping strategies and build up their confidence during the first hospital stay especially when dealing with a hereditary disease.

The role of health care personnel can be catalytic as it has been shown that drugs alone can not successfully treat the child who suffers from severe pain, anxiety, or is in denial. The nurse's role is to support, inform, educate, with regard to the care and treatment of the child and prepare the child and his parents in order to adapt to the new circumstances of the illness. The ward where the child with chronic illness is hospitalized must have equipment to engage the child in group activities (table games, painting, etc). In this way the child does not remain inactive, adopting a "being sick role", with all the negative psychological consequences that this carries.

In addition, psychological insight can be provided by a Psychiatric Advisory-Liaison Service, which can solve specific problems in a paediatric clinic. When the health care team intervenes early, it facilitates the child and his family to adopt constructive ways and methods of confronting the condition. The best period for this psychological intervention is during the initial phase of diagnosis, when the family finds itself in a crisis and its members try, select and adopt ways of coping that determine the short-term and long-term adaptation to the chronic illness.<sup>26</sup>

Without doubt, the announcement of a chronic condition to the family is a traumatic experience, which shakes the parents as they realize that their child's autonomy is threatened. This also applies to the nursing team who has to deal with a difficult and emotionally harrowing experience, particularly if the team members have not cultivated and developed suitable support bonds amongst them. The nurse's ability to communicate effectively with the suffering child and his family requires ongoing professional development and continuing education. During the initial medical briefing the two most important qualities that parents expect the nurse to practise is sincerity with a glimmer of hope, regardless of the seriousness of the child's condition. When sincerity is shown, confident relationships, cooperation and collaboration are established. Similarly, when there is hope, no matter how small, the family can motivate internal forces in order to face the difficult new reality.<sup>27,28</sup>

Information for parents should be continuous, corresponding to the stages of development of the illness and include new circumstances as they present, also taking into consideration the parents' anxieties. The information should be given in the form of a discussion dialogue so that the parents are able to respond, express themselves and ask questions in order to prevent misunderstandings. This approach informs us of their fears and sentiments as well as providing time for questions to be tackled as they arise.<sup>29</sup>

Time is needed for discussion and reflection on the needs of both the child and the caregivers if constructive change is to take place. The language that we use can be scientific but direct and, where

necessary, simplified. We need to find a balance between being objective and compassionate, yet avoiding the extremes of sentimentality or downgrading the harshness of the reality. When both parents are seen and instructed simultaneously this can provide further bonding of the couple. Their ability to face responsibilities together reassures each of them and the strength benefits their suffering child.<sup>30</sup>

So as far as the nursing personnel are concerned, the primary need is to gain collaboration. Therefore the basic objective aims should be to:

- a) encourage an open channel of communication between members of the family
- b) offer continuous support and an optimistic attitude
- c) offer allocation of extra time when a crisis occurs
- d) prepare the parents, or other care givers, to the actual phases of the child's treatment
- e) prompt the child and the parents to play an active role in the treatment<sup>31,32</sup>

The nurse who can inspire a child to act responsibly concerning his condition has a truly valuable skill. Any child who strives to apply well directed self-help will reap long-term advantages. Such positive approaches constitute a sound base for the equitable relation of reciprocal confidence and respect between the therapeutic team and the suffering child.<sup>33</sup>

The question of whether the child should or should not be informed of his disease or disorder and its treatment has been debated for many decades. It is now well acknowledged, from studies and clinical experience, that the children who are wounded mentally is aware of the gravity of their situation, even when this is not mentioned directly to them. When a child is not informed, being confronted with a "wall of silence" increases his stress and supplies his fantasies, which are often more threatening or terrifying than the reality itself. Children with a life-threatening illness experience increased stress especially when discussion of the subject has been prohibited from the initial stages of the illness. Often, however, a child in middle childhood, may cooperate with this pretence, which prohibits discussion, and may attempt to hide an inner fear - even the possibility of death - believing this behaviour will 'protect' his family from such feelings of shame or embarrassment.<sup>34,35</sup>

The appropriate time for briefing, should be individualised for each child and the information and style of approach should be adjusted in each case depending on age, the stage of their intellectual growth, personality, his family environment, financial circumstances, as well as the physical and psychological situation at the time. Children need an individualized approach with regards to what is happening or what might happen to them. Each one should be given time to express different concerns and ask questions, each seeking different assurances and answers. It is important that the nurses understand the emotional world of the child, its cognitive faculties, how the child perceives the significance of health and illness so they adjust the information and style of delivery accordingly using tact and diplomacy. Care should be taken to prevent misinformation which may be why some health care personnel would rather avoid discussion for fear of frightening the child, as well as having doubts about their own ability to handle the discourse sensitively. As mentioned earlier, the necessity for training in this domain is becoming more recognised.<sup>36,37</sup>

## **Rehabilitation**

Various factors contribute to the development of the child with chronic illness. To face the situation effectively, when parents have realistic attitudes towards the illness these can offer emotional relief for the child and constitute a base for his treatment. The capacity of the child to adapt is made easier when encouraged to participate in the treatment of his illness and when only realistic restrictions on his lifestyle are imposed. Encouraging educational and recreational activities as well as the regular follow-up of school activities especially during hospitalisation have proved beneficial.

If the parents are forewarned and prepared they can remain calmer when a crisis looms improving their ability to deal with the situation. These attributes will contribute positive signals to the child

who in turn will improve his own ability to function when things go wrong. When families are unable to turn negative experiences into positive outcomes or they fail to develop effective forms of communication, then the intervention of mental health experts is vital. Social service support or family therapy at such times can be invaluable and improve the functioning of the caregivers and the quality of life of the child.<sup>38</sup>

The re-establishment of coping strategies often requires social rehabilitation as well as psychological support. What is needed is co-ordination of available offered care so that the best possible results can be achieved, yet in many areas such support is seriously lacking in Greece. The establishment of centres for rehabilitation within hospital services is essential. The benefits of improved care can arise with careful and realistic planning and training of health specialists, many already within the hospital system. A rehabilitation team should involve the participation of the parents of the child with experts such as the paediatrician, physiotherapist, speech therapist, psychologist, educators, social worker, community nurses and others. The role of a psychologist in this team is decisive when the diagnosis of the child includes mental disturbances. Where there are major domestic upheavals individual or group therapy might be recommended. The attendance of other family members or other children may be advantageous especially when they are of the same age.<sup>39,40</sup>

A study on how team work benefits chronically ill children was conducted at the Psycho-paediatric Department of the Psychiatric Clinic of "AHEPA", University Hospital, Thessaloniki. This research involved two counselling teams working with cases of children with leukaemia. One team occupied the children through painting, discussion and games while the other focused on the parents teaching techniques to release tension, discussing sentiments and introducing them to mutual support groups. The main outcome was better adaptation and improved collaboration with paediatricians and other health professionals.<sup>41</sup>

Social support is a very important factor in the confrontation of chronic illness. Children who are the recipients of support by parents and peers present considerably more improved capacities to adapt and show fewer behavioural problems compared to children that have only marginal sources of support.

Where adaptation is poor, children with chronic illness are prone to frequent and long-lasting hospitalisations requiring them to be removed from their family environment. These situations can cause further stress, fear and negatively affect the relationship with the parents. Research confirms that children who have been frequently hospitalized are at increased risk of sleep disruptions, alimentary disturbances, melancholy, social isolation, psychosomatic disorders, excessive fears / phobias, pathological dependence on the mother, and some regress to finger sucking and nocturnal enuresis.<sup>42</sup>

Another project that took place at the Paediatric Clinic of the Penteli Children's Hospital, Athens, observed that:

- hospitalized children often presented with disturbances of behaviour such as aggressiveness, cantankerousness, fear of bodily harm, emotional regression and disrupted appetite and sleep patterns
- these disturbances were partially due to certain factors within the family such as stress, fear of the unknown hospital environment, fear the illness, and changes in usual activities
- some hospitals had compounded the problems due to staff shortages, insufficient time available with medical and nursing personnel and limited or no specialised education
- the socio-economic status and level of education level of the parents also played an important role

It was concluded that numerous negative psychological repercussions of hospitalisation could be blunted with the presence of family members learning simultaneously with the child. Psychological support of the child from specifically educated hospital personnel gave favourable outcomes.<sup>43</sup>

Without these systems in place, hospitalisations consequently impede the faculty of the child physiologically, and disrupt interpersonal, familial and social relations that are important for physiologic growth and maturation. Caring for the child at home is preferable because it supports the child and promoted independence as well as promoting the institution of family and its traditional roles.

Home care makes enormous demands on family members and it is only fair that society should shoulder some of these responsibilities by providing well trained medical and paramedical teams to support these children and their care-givers. The use of specialised clinics or programs to back up home care is proven to be the most humane approach of care for these disadvantaged children. Despite the need for careful planning and co-ordination between the family, hospital, social services, schools and the other structures that participate, as well as the evaluation and continuing professional development of the team, this system which supports home care for families and children is also proven to be the most cost effective of all. The fundamental objective of such programs for children or adolescents with chronic illnesses is their effective care in the protected environment of the family, which maximizes their possibilities and minimises the results of illness or their infirmity.<sup>44</sup>

The work of all experts that are involved in the rehabilitation of a child with chronic illness is indubitably multiple and complex, because it needs:

- a) an early diagnosis in order to decrease the negative consequences of the illness
- b) facing the bodily and psychological problems of the child
- c) checking the stresses and circumstances that cause relapses
- d) strengthening the child's will to adopt a constructive, preventive approach to his illness
- e) an awareness of the economic, social and psychological problems facing the child and family

In the case of children with chronic illness or infirmity it is the responsibility of all appropriate institutions to rise to the challenge and help assist the family. But also as individuals we need to show essential sensitivity, to offer support when possible and to recognise the enormous demands and responsibilities on the families involved. Where social services do not exist, every effort should be made to create centres of rehabilitation, which can organise programs of care and support for the sick child and the often neglected home carers, especially when poverty is an additional burden.

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