### ORIGINAL ARTICLE

# Psychosocial and psychiatric aspects of children suffered from chronic physical illness

Daniela Jelenová<sup>1</sup>, Ján Praško<sup>1</sup>, Marie Ocisková<sup>1</sup>, Radovan Hrubý<sup>4</sup>, Markéta Maráckova<sup>1</sup>, Miloš Šlepecký<sup>4</sup>, Jana Vyskočilová<sup>5</sup>, Michaela Holubová<sup>1,6</sup>, Martina Hunková<sup>1</sup>, Dana Kamarádová<sup>1</sup>, Klára Látalová<sup>1</sup>, Vladimír Mihál<sup>2</sup>

- <sup>1</sup> Department of Psychiatry, University Hospital Olomouc, Faculty of Medicine and Dentistry, Palacky University Olomouc, Czech Republic.
- <sup>2</sup> Department of Pediatry, University Hospital Olomouc, Faculty of Medicine and Dentistry, Palacky University Olomouc, Czech Republic.
- <sup>3</sup> Outpatient psychiatric department, Martin, Slovak Republic
- <sup>4</sup> Department of Psychology Sciences, Faculty of Social Science and Health Care, Constantine the Philosopher University in Nitra, Slovak Republic.
- <sup>5</sup> Faculty of Humanities, Charles University in Prague, Czech Republic.
- <sup>6</sup> Department of Psychiatry, Hospital Liberec, Czech Republic.

Correspondence to: Jan Prasko, Department of Psychiatry, University Hospital Olomouc, Faculty of Medicine and Dentistry, Palacky University Olomouc, Czech Republic. e-mail: praskojan@seznam.cz

*Key words:* 

chronic children illness; quality of life; psychological problems; psychiatric diseases; pharmacotherapy; cognitive behavioral therapy

Act Nerv Super Rediviva 2016; 58(4): 123-131 ANSR580416A08

© 2016 Act Nerv Super Rediviva

## **Abstract**

The link between a physical illness and a psychological disorder in children and adolescents is well explored. Chronic somatic illness encompasses a broad spectrum of disorders including more common problems such as diabetes mellitus, obesity, asthma, epilepsy, eczema, and less prevalent conditions such as cystic fibrosis, hematological disorders or cancer. Many children more or less successfully adapt to live with chronic physical conditions. However, others suffer from various types of distress. Chronic illness doubles the risk for behavioral and emotional problems. If the medical condition is associated with a visible physical deformity, the risk is triple.

The prevalence of social-emotional difficulties in children with chronic illnesses is higher when compared to healthy children. Liaison child psychiatrists commonly encounter adjustment disorders, acute stress reactions, posttraumatic stress disorder (PTSD), anxiety disorders, and depression in child pediatric hospitals. These psychiatric disorders may occur both during the treatment of a somatic disorder, or they may have onset later in the life (during adolescence or adulthood).

## Introduction

There are about 4% of children in the Western countries that are affected with chronic physical illness (defined as disorders that last at least one year and are associated with persistent or recurrent handicap) (Cadman *et al* 1987). Most children's illnesses are only minor and transient and cause only temporary

disruption of everyday life. However, it is estimated that 2–3% of children have medical illnesses that are severe enough to interfere with growth, development, school performance or social relationships (Drell & White 2005). In children is psychological well-being connected with several associated features – a nonap-

pearance of psychological symptoms, involvement in age-adequate tasks and activities within the family and wider community, and feelings of positive self-esteem (Immelt 2006). Chronic diseases pose an ongoing challenge to children and their caregivers. Most families adapt successfully and find a new equilibrium that balances the impact of illness with needs of the child and the rest of the family. As developmental, biological, psychological, and social circumstances change, new adaptations are required to prevent future problems.

The link between physical illness and psychological disorder in children and adolescents is well established. Hospitalization in the pediatric intensive care unit (PICU) increases the risk of chronical psychological and behavioral problems following discharge. Despite enormous advances in diagnostic technology and treatment strategies, about 25% of children show psychological problems after discharge (Rennick *et al* 2014).

While PICU outcome research has historically concentrated on physical recovery and predictors of child mortality, research over the past three decades has increasingly focused on psychological and behavioral responses (Carnevale 1997; Judge et al 2002; Rennick et al 2002; Connolly et al 2004; Rees et al 2004). Parents refer to declines in children's self-esteem and emotional well-being, bigger anxiety and harmful behavioral alterations (e.g., sleep disturbances or social isolation) after discharge from the hospital. School-aged children report increased medical fears, anxiety, delusional memories, and hallucinations, changes in friendships and their self-confidence (Rennick & Rashotte 2009). Psychiatric disorders, together with PTSD and major depression, have been also diagnosed (Rennick & Rashotte 2009; Davydow et al 2010). Other diagnoses commonly encountered by consultation-liaison child psychiatrists in pediatric care of chronic ill children include adjustment disorder, acute stress reaction, anxiety disorders, and chronic fatigue (Bell et al 1991). These studies have usually been directed at the first year post-PICU with the majority assessing symptoms within the first six months (Rennick & Rashotte 2009; Davydow et al 2010; Colville 2008). Nevertheless, health-related quality of life (HRQoL) research suggest that deterioration in children's emotional well-being may be longer-lasting (Jayshree et al 2003; Colville et al 2013, Knoester et al 2007; Taylor et al 2003). In fact, there is a lack of data regarding the 12- to 36-month period following PICU hospitalization.

# QUALITY OF LIFE IN CHILDREN WITH CHRONIC SOMATIC ILLNESSES AND THEIR FAMILIES

The prevalence of social-emotional difficulties in children with chronic diseases is higher compared to healthy children. It is well understood that our perception of health in situations of chronic disease can be affected by the outlook and coping mechanisms. Literature indicates that children with chronic illnesses

manifest more internalizing problems like depressive syndromes (Boekaerts & Roder 1999; Evans *et al* 2005). Because of inextricable links between young people and their family, it is inappropriate to consider symptoms as an index of child in isolation. The effect of symptoms on family functioning, parent, and sibling relationships should be considered (Gledhil & Garralda 2009; Van de Loo *et al* 2013).

Due to enhanced treatment opportunities and more positive consequences of life expectation, the amount of chronically ill kids who live longer is growing, and more pediatric patients with somatic illnesses live into adulthood (Perrin et al 2007). For these children, transition into adulthood is a critical period. Children with chronic diseases are anticipated to go through analogous developmental phases as their healthy peers (Hallum 1995). For children with deficiencies, the realization of these developmental steps can be challenging. Several survey showed that school-aged kids with chronic disorders, irrespective of their diagnosis, are more restricted in their involvement in daily life than their peers (Law et al 2006; Stam et al 2006). Also, investigation has displayed that adolescents with disabilities often follow atypical developmental patterns when compared to their healthy peers (Hartman et al 2000; Stam et al 2005; Verhoof et al 2012) They are at risk of reduced educational, career and social outcomes in adulthood (Calsbeek et al 2002; Stam et al 2006; Lindsay 2011; Maslow *et al* 2011).

# PSYCHIATRIC ASPECTS OF CHRONIC PHYSICAL ILLNESS IN CHILDREN

Chronic somatic illness encompasses a broad spectrum of disorders including more common problems such as diabetes mellitus, obesity, asthma, epilepsy, eczema, and less prevalent conditions such as cystic fibrosis, hematological disorders or cancer. Many children more or less successfully adapt to chronic physical conditions. It can be connected with various types of distresses for children and their families (Gledhil & Garralda 2009).

There are several types of distress associated with chronic illnesses in childhood. Also, in the presence of disease itself, diagnostic and treatment strategies may be stressful or have severe side-effects like alopecia, obesity, and scars. Some demands or rules of treatment, such as dietary restrictions or routine, may be difficult. Many of these conditions may lead to difficulties in relationships with peers. Also, the hospitalizations may result in interruptions in schooling and participate in leisure activities with peers.

Some factors related to the child, and his/her disease have been described to contribute to the likelihood of developing psychiatric disorder (Gledhil & Garralda 2009):

- nature of the physical illness, effects of disease and treatment procedures;
- stage of the disease;
- the severity of illness or degree of life threat;
- psychosocial risk and protective factors in the family;
- age and developmental stage.

### (1) Variables that determined by the nature of the illness

Chronic diseases pose an ongoing challenge to children and their caregivers. Illness-related factors, such as it is life-threatening, painful or causes visible or permanent disability, may influence children differently (Drell & White 2005). The disorders affecting the brain have a higher prevalence of the psychiatric disorders, especially when epilepsy is involved (Rutter et al 1970). Children with brain dysfunction (such as epilepsy or cerebral palsy) may be more likely to exhibit externalizing disorders such as hyperactivity (Rutter et al 1970). Psychiatric disorders in this group of children may be persistent, with 70% experiencing difficulties at 4year follow-up. Overactivity, restlessness, and inattention are the best predictors of persistence. The risk in children with a chronic physical illness that does not involve the brain is lower and only slightly increased over general population rates.

In illnesses not affecting the brain, the psychiatric problems seem most likely to be not associated with the big amount of generic stress factors and family changes common to living with a chronic illness (Gledhil & Garralda 2009). These include life stresses such as hospitalization, specific dietary requirements and disruption of family routines (Eiser 1993). These children are more prone to develop emotional symptoms and eating abnormalities. Illness can generate a family and social stresses and changes that are known as risk factors for the development of the emotional disorder in children. This includes mood disorders in parents and overinvolved and overprotective parenting (Garralda & Palance 1994).

The perceived severity of the diagnosed illness is important. The diagnosis of cancer continues to terrify people, despite there are numerous advances in medical treatment that have considerably decreased morbidity, and mortality. The importance of education in these conditions cannot be underestimated. Also, the perception of how the child got the illness makes a difference (Drell & White 2005). If the disease is genetic, the parent of the family with the trait may deal with feelings of guilt or accusations and concern about siblings or future generations. Rare diagnoses can cause distress and bewilderment. Families often report feeling to be isolated by having a child with a disorder that sparks no recognition among peers or medical personnel. This isolation is lessened somewhat by information gained from the internet and communication with families with the same experience.

Both children and also their parents and sometimes whole families experience increased difficulty when the illness brings visible deformities or disabilities. Children and youth with a physical deformity have a three times greater risk of developing mood disorders (Drell & White 2005). Physical deformities are especially burdensome for adolescents who are overly sensitive to the body image. The impact of the deformity or disability must be also seen in the context of the whole family. For example, a minor disability of the leg that threatens the football career of the child is more corrosive than the same disability in the child fascinated by music.

### (2) Stage of the illness

The time of the early diagnosis is crucial. For example, one-third of children with insulin-dependent diabetes mellitus in one study (Kovacs *et al* 1985) developed an adjustment disorder, and 50% of them recovered within two months. Similarly, psychological problems were seen in 60% of children with chronic renal failure at the time of starting dialysis. One year later, the prevalence of disturbance was reduced to 21% (Wass *et al* 1977).

# (3) Severity of illness

There is a higher risk of psychiatric disorders in children with the more severe physical illness. Children with more severe chronic renal failure, who require hemodialysis, have been found to have the more psychiatric disorder than those not requiring dialysis (Garralda et al 1988). Children with a history of hospitalization for ketoacidosis in the previous year are more likely to develop a psychiatric disorder than a group of patient with insulin-dependent diabetes mellitus without ketoacidosis last year (Liss et al 1998). Higher levels of PTSD symptoms have been found in children and parents up to a year after admission to Paediatric Intensive Care Unit and the following admission to general pediatric wards (Rees et al 2004), and up to 10 years after treatment of childhood cancer (Kazak et al 2004). There is growing evidence that emotional parental response to the child's traumatic experience predicts the child's level of PTSD and other symptomatology (Cohen 2005).

# (4) Psychosocial risk and protective factors in family

Psychiatric symptoms in children who are physically ill are often attributed to the presence of the illness and its stress (Gledhil & Garralda 2009). However, in reality, the influence of predisposing factors is also critical. A biological predisposition (diathesis) to a mental disorder could become manifested because of the stress of chronic somatic illness or the medications used to treat it. Among common predisposing factors, there are a genetic vulnerability, temperamental characteristics, marital disharmony in the family, lack of open communication, maternal illness affecting parenting (depression, schizophrenia, etc.), bullying in the school or poor peer relationships. Personality factors,

e.g. whether a child is anxious or oppositional, influence how the child perceives the illness and his or her involvement in treatment (Drell & White 2005). Recent research has shown that children, who are more anxious, tend to be more compliant with treatment regimens (Gledhil & Garralda 2009). Pediatric psychiatrists described regulatory disorders that are characterized by young children having difficulties to regulate aspects of their functioning, such as behavior, affect, physiology, attention, and the senses. These regulatory disorders include subtypes, such as hypersensitive (overreactive), underactive, and motorically disorganized or impulsive (Drell & White 2005).

Most families adapt efficiently and find a new equilibrium that balances the needs of the illness, the child, and the caregivers. The central questions focus on the strengths and weaknesses of the support systems of the caregivers. Factors, such as family functioning, peer relations, and traditional beliefs and attitudes, also have an impact on a child with a chronic medical illness. These factors do not have a one-direction influence. The child's illness influences members of the family, peers, and others (e.g., teachers), and they, in turn, can affect the child. On the other side, protective factors, like secure parent-child attachments, increase family support in response to physical diagnosis, as well as sensitive pediatrics management of hospitalizations, may reduce the risk of developing a psychiatric disorder caused by stressful medical procedures.

Societies and cultures vary in their views on illness. These variances can also significantly influence the course of the disease and its treatment (Drell & White 2005).

## (5) Age and developmental stage

The chronic diseases influence a child differently when diagnosed as a teenager versus as toddler, for example. There are developmental periods when the illness can show a greater impact on emotionality and behavior. Early childhood and adolescence are particularly sensitive periods.

Preschool children have less cognitive resources to cope with the discomfort and stressful medical procedures and are likely to rely on parental support and distraction to deal with illness. It is further complicated by fears of separation from the attachment figure (Drell & White 2005).

Children between four and seven years of age may believe that illness has been caused by something bad they have done and that they should be punished for (Gledhil & Garralda 2009). Sticking to parents, anxiety, fearfulness, sleep problems, and oppositional-defiant behavior is seen in preschool children. For school-age children, return to school after chemotherapy can be associated with the development of school phobia and social isolation. Many school absences, teasing, and even bullying, especially of those children who look dif-

ferently, may also assist to lowered self-esteem and the risk of affective disturbance.

A greater understanding of the consequences of chronic illness and the threat of death leads to more recurrent depression in adolescents. In adolescence, the illness threatens the general push toward autonomy and necessitates more dependency on parents and other adults. Adolescents can also challenge and experiment with their treatment. There may be a decline in compliance with medical advice and adherence to the treatment regimens (Eiser 1993).

# MOST FREQUENT PSYCHIATRIC DISORDERS IN CHILDREN WITH CHRONIC SOMATIC ILLNESS

The association between psychiatric problems and physical illness in children received attention in psychiatric epidemiology only recently (Cohen et al 1998, Chavira et al 2008; Merikangas et al 2009). However, it is estimated that 2-3% of all children suffer from medical illnesses that are severe enough to interfere with growth, development, school performance, or social relationships. Some studies illustrate that children with the physical illness have an increased risk for depression (Cohen et al 1998). On the other side, some studies have shown that children with psychiatric disorders are more likely to develop somatic disorders (Parry-Langdon et al 2008). There are also studies that investigated the biological relation between psychiatric and somatic disorders such as diabetes and mood disorders (Stewart et al 2005), and anxiety disorders and asthma (Goodwin *et al* 2004).

Many diagnoses in psychiatry have somatic criteria (e.g., loss of energy and decreased appetite), that must be evaluated in the context of the illness. Some consultation-liaison psychiatrists put a greater emphasis on somatic a psychological signs, such as loss of hope, suicidal thoughts, feelings of worthlessness, and depressed mood. However, it is important to recognize that many adolescents adapt to their illness, and they report relatively normal sleep, appetite, and energy level.

Depressive symptoms appear to be characteristic of adjustment disorders in children and adults, although behavioral symptoms and different presentations are seen more frequently in this groups. Chronic sleep curtailment from infancy to school age was linked with higher overall and central adiposity in mid-childhood (Taveras *et al* 2014). The adverse effects of sleep curtailment on obesity was consistent across infancy, early-, and mid-childhood and no evidence was found for an especially critical period.

Functional or medically unexplained somatic symptoms in children establish a significant medical difficulty (Berntsson *et al* 2001; Domènech-Llaberia *et al* 2004; Eminson 2007; Rask *et al* 2009; Strine *et al* 2006) and account for about 10–15% of visits to medical services (Blum 1986; Garralda & Bailey 1987; Gieteling *et al* 2011). However, research facts on functional somatic

symptoms in young children are few, and epidemiological studies are disadvantaged by the absence of well-standardized measures (Rask 2012). According to the symptoms, these children may experience numerous investigations and treatment methods, which can influence their well-being and establish a substantial cost burden on society (Campo et al 2002; Lindley et al 2005; Geist et al 2008). Functional somatic symptoms features were linked with medicinal discussion: multisymptomatic presentation and the symptoms with subsequent impact on different aspects of life (e.g., child distress, school/kindergarten nonattendance, and family burden). This result is in agreement with outcomes from studies of adults with functional somatic symptoms and corroborates the understanding of them as a range of symptoms fluctuating from mild self-limiting problems to severe and disabling disorders (Katon et al 1991; Fink et al 2005).

# MANAGEMENT OF PSYCHIATRIC PROBLEMS IN CHILDREN WITH CHRONIC SOMATIC ILLNESS

The rigorous research in this area is absent. The most guidelines of the psychological care of children with physical illness are based on clinical practice. Interventions should be directed at mitigating risk factors and reinforcing and supporting of active coping mechanisms in a child, family, and caregivers. The goal is to promote the healthiest possible functioning among all concerned and to return families to a typical developmental trajectory.

Child psychiatrists frequently work closely with pediatric colleagues to assist in identifying children at risk for psychiatric disorder and to provide treatment when indicated, as well as to give support and advice for diagnosis and management. Pediatricians, child psychiatrists, and psychologists have joined forces in the growing areas of pedo psychiatry and pediatric psychology, collaborating to foster the health and developmental needs of children and their families.

Chronic medical illness in childhood may occur during crucial developmental periods. Every step in the therapy must be taken with the assurance that disruption of education, social, recreational, and peer group progress occurs for as short a period as possible unless there is compelling evidence to the contrary "wait and see" approach is contraindicated (Bell et al 1991). Active management involves a variety of methods. The right choice of method will depend upon the degree of disability of the child, the view of the family, and the available resources (Wessely et al 1999). It always involves work with a whole family to promote increased activity and decrease illness behavior. Behavioral activation packages (Feder et al 1994; Vereker 1992; Wachsmuth & MacMillan 1991; Sidebotham et al 1994) have given very encouraging results, often linked with a family therapy approach (Pipe & Wait 1995). In some case graded reintegration to school must be encouraged as early as possible (Dale & Straus 1992).

Involvement of parents is essential in all steps and levels of treatment. Treatment problems may happen when the parents think that active rehabilitation would be harmful or dangerous (Rikard-Bell & Waters 1992; Vereker 1992). Sometimes one member of the family, usually the mother, is overprotective of the child, which leads to a fixed sick role that can be difficult to alter. The loss of regular peer group interactions reinforces the dependence of the child on the family (Garralda 1992).

When there is a chronically ill child in the family, parents often find it difficult to maintain the usual boundaries. For example, disciplining an ill child may be associated with parental guilt; this can lead to increasing anxiety for children who exhibit increasingly oppositional behavior to test the boundary limits. Discussion regarding parenting techniques in the context of these feelings may be helpful. Parents also tend to increase their protective responses to ill children and show more overinvolved parenting. If excessive it may impede the child's development, but to a modest degree, it may be helpful and advantageous (Gledhil & Garralda 2009).

It is important to know the child's previous developmental profile and to assess current symptomatology, arrests or regressions (Lederberg 2005). Preexisting disorders can be aggravated by chronic illnesses and must be monitored and treated. The stress of chronic illness can make a mild psychiatric disorder to manifest for the first time. Anxiety, depression, and sometimes delirium occur routinely in children and respond well to treatment. Anxiety is ubiquitous at the date of diagnosis of physical illness and at the time of starting the treatment. Behavioral interventions are the first line of treatment, but some situations may require the use of anxiolytics. Benzodiazepines are used but can cause a disinhibition syndrome that may be mistaken for more anxiety. Depressive symptoms are common and rarely progress to severely retarded depression with a somatic syndrome that responds to low doses of antidepressants. Paroxetine treatment had been reported to predispose children to suicide; warnings were issued for the use of SSRIs in children. However, experts point out that the evidence is not high enough to warrant a categorical prohibition and suggest safe use with close monitoring (Lederberg 2005).

Psychological interventions may help children with adjustment disorders. Management may include ways of decreasing existing stress or helping individuals to adjust. Possible interventions include supportive counseling, individual therapy using cognitive-behavioral principles, and family therapy.

Recent work on PTSD in children reinforces the belief that aggressive prophylactic relief during difficult procedures is essential not only for current comfort but also for long-term adaptation. Poorly managed painful procedures not only brutalize the child, but also result in anticipatory fear of pain, loss of trust and cooperativeness, phobias, and posttraumatic symptoms that do not improve over time (Lederberg 2005).

Systematic desensitization together with relaxation and distraction techniques may be used to treat a specific needle phobia. This needs to be carried out in cooperation with ward staff and taking into account associated psychopathology, for example, a generalized anxiety state, oppositional behavior, or an adjustment reaction.

Generalized symptoms of anxiety are not uncommon in parents and children and can appear in different ways. A young child may resume bed-wetting; a school-age child may become intensely distressed by being away from parents, adolescents may experience sleep difficulties, and anxious parents can become agitated with ward staff. Regular explanations from staff about the child's condition and treatment may help to alleviate this anxiety. Communication difficulties within the family may contribute to anxiety and could be supported by family meetings where difficulties can be shared. Relaxation and distraction techniques together with cognitive behavioral interventions may also be of benefit. If symptoms are intense and interfering with physical treatment, anxiolytic medication can be indicated.

The pediatric literature is supplied with information on how to deal with the so-called involved parent. This usually refers to parents who are extremely demanding, overbearing and want to dictate the treatment plan for their children, even at a time when their approach is not medically indicated (Drell & White 2005).

## **Pharmacotherapy**

Efficacy, adverse events, and safety of the pharmacotherapy used in children with psychiatric problems were broadly discussed, particularly due to lack of evidence about long-term effects (Raz 2006; Wohlfarth *et al* 2009). Also, a relation between the administration of selective serotonin reuptake inhibitors and increased risk of suicidality has been found in the children population and adolescence (Hammad *et al* 2006; Stone *et al* 2009).

Antidepressant medication may be considered for children and adolescents with a depressive episode. This should be discussed with the medical team to minimize drug interactions and side-effects that may exacerbate the physical condition of the patient.

### *Psychotherapeutic approaches*

Chronically sick children are benefiting from social and psychological empowering. They are being informed more honestly, and their cooperation is being thoughtfully enlisted. It has become evident that, as in adults, children know or intuitively perceive a great deal without being told and are relieved by open communication. Such provision is complicated by the need to be

age appropriate and is more painful because of adult vulnerability to see suffering in the youngsters. As a result, adult denial often prevails, and children respond with increased behavioral symptoms or withdrawal (Lederberg 2005). A child with cancer can hardly remain oblivious to the endless clinic visits, repeated chemotherapies, repeated exposure to other patients, noticeable symptoms, such as hair loss, weight and body changes, and concerned speeches of individuals around them. Studies suggested that immediate perception outweighs distant reality, especially in younger children. Discussions are openly designated, but they must follow the child's lead, observe the sources of anxiety and remain reassuring about care and comfort if he or she cannot be so about the result. Kids, who receive open facts, have less consequent anxiety than children who do not. However, parents often invite and profit from psychotherapeutic guidance about how to proceed, because telling the truth to young children is strongly molded by the child's circumstances and level of possible understanding. This is not always se obvious even for the most loving parents. However, they usually learn and are very responsive to guidance (Lederberg 2005).

Few training programs exist for preschool children with emotional or behavioral problems linked to somatic diseases. There were some programs for the behavioral problems for the preschool children. Metaanalyses have shown that social training programs can improve social and emotional skills and reduce behavioral problems in preschool children (Beelmann 2012). The effect of the social training program for preschool kids with severe behavioral difficulties designed to increase emotional knowledge and regulation, the ability to take another person's point of view, communication skills, and social problem solving, was significantly better than in controls (Schell et al 2015). Remarkable advances in prosocial problem-solving strategies were distinguished in the kids who underwent the training program immediately after the intervention as well as five months later. This shows that the children had considerably more positive strategies that were available to cope with difficult social situations than the children had in the control group.

### Cognitive behavioral therapy

Some authors have gone even further by proposing that a cognitive model of illness provide the most thorough understanding of these clinical symptoms, amplifies our conception of etiology, and has significant treatment implications (Surawy *et al* 1995). Cognitive models suggest that distorted thoughts and underlying assumptions about illness and personal coping abilities interface with actual pathophysiologic mechanisms or vulnerabilities to physical symptoms. Once symptoms have begun, further faulty cognitions, inadequate coping mechanisms, negative mood states, and social dysfunction interact to create a vicious cycle that

maintains the illness. Given Beck's theoretical model of depression as a biological entity with cognitive, behavioral, and emotional components that influence each other to produce and perpetuate illness, cognitive behavioral therapy seems to be inherently well suited for the treatment of the "psychosomatic" patient.

#### PARENTS DISTRESS

The families of pediatrics patients are even more vulnerable than those of adults because of the child's total dependency and the biological, emotional, and social factors that make families uniquely responsible (Lederberg 2005). Any intervention has no chance of success if it does not address the family as much as the child. Family interventions have helped to relieve the suffering of family members who care for children with chronic illness. Family members of children with chronic somatic illnesses may suffer from financial difficulties, limited social lives, loss of recreation, and constant worry and vigilance (Griffith & Slovik 2008). Family members, in turn, impact both the psychological well-being and capacity for disease management by the ill child or adolescent. Family psychoeducation may reduce family burden for caregivers of patients with chronic somatic illness (Heru 2006).

### STAFF ISSUES

Treating children with severe disease, who may receive distressing and painful treatment, can arouse intense emotions even in the most experienced pediatric team. Regular meetings with mental health professionals may help them to process some of these feelings and prevent them impeding patient care.

### BARRIERS TO THE TREATMENT

Another significant barrier to treatment using CBT for these disorders is the acceptability of the treatment by "non-psychiatric" populations. Though CBT appeared acceptable to study participants in many of the above trials, real-world patients are likely to see a doctor's recommendation of CBT as a belief that symptoms are not real but are imaginary instead (Price & Couper 1998). Patients with "psychosomatic illnesses" often reject any implication that psychological processes affect their condition (Surawy *et al* 1995).

# PROGNOSIS OF PSYCHIATRIC DISORDER IN CHILDREN WITH CHRONIC PHYSICAL ILLNESS

Many of the psychological difficulties experienced by chronically ill children are short-term and do not continue into adult life. Persistence of disorder is related to the severity of childhood psychological symptoms, the persistence of physical symptoms into adulthood (Pless *et al* 1989), and to the presence of physical disorder affecting the brain (Gledhil & Garralda 2009).

Many studies suggest that in adulthood, most survivors of childhood cancer are indistinguishable from the general population in the psychosocial outcome. However, the more detailed analysis suggests that factors such as age at diagnosis, a position/placement of the tumor, and nature of the treatment may influence the cognitive and psychological outcomes. For children and adolescents diagnosed with brain tumors, cognitive deficits, and psychological problems increased with age and time since diagnosis (Poggi *et al* 2005).

Bass and Murphy (1995) suggested that a history of childhood victimization and a lack of parental care, combined with severe illness early in development, may increase the likelihood of hypochondriasis in individual who are prone to approach their environment in an anxious, dependent manner. As a survival has increased, adults are exposed to the chronic toxic effects of treatment such as endocrine abnormalities, cardiac or pulmonary problems, and infertility. Follow-up of childhood cancer survivors with a mean age of 28 years revealed that current physical functioning, including pain, was associated with suicidality even after accounting for treatment and depression variables (Stone *et al* 2009).

Individuals with intracerebral pathology maintain high levels of mental disorders in adulthood, especially behavior problems, and social isolation. By contrast, patients with congenital heart disease surgically corrected in childhood do not show the increased risk of psychiatric disorder in adulthood. The majority of adult renal patients are reported as functioning socially well, but they are more likely than age-matched controls to live with their parents, to have fewer school qualifications, higher rates of unemployment, and fewer intimate relationships outside the family.

### **Conclusions**

Changes in physical health can affect the psychiatric outcome. Conversely, emotional problems may affect adherence to the somatic treatment. Awareness of this interplay is essential and should be mirrored by a close working relationship between pediatricians and child psychiatrists and psychologists. With the acknowledgment of the psychosocial impact of a physical condition in childhood on psychological wellbeing in later life comes the need for increasing awareness to develop supportive psychosocial programs (Logan et al 2013). Systematic assessment of psychical and emotional functioning is not the part of usual practice yet, but effective routine assessment of emotional well-being could easily be implemented in daily clinical practice for children with computerized and web-based patient reported outcomes (Haverman et al 2011, 2013; Engelen et al 2012; Verhoof et al 2014).

#### ACKNOWLEDGEMENT

Supported by research grants IGA MZ ČR NT 11047-4/2010.

#### **REFERENCES**

- 1 Bass C & Murphy M (1995). Somatoform and personality disorders: Syndromal comorbidity and overlapping developmental pathways. J Psychosom Res. 39: 403–427.
- 2 Beelmann A (2012). The scientific foundation of prevention: The status quo and future challenges for developmental prevention. In: Bliesener T, Beelmann A, Stemmler M, editors. Antisocial behavior and crime: Contributions of developmental and evaluation research to prevention and intervention. New York: Hogrefe Publishing, p. 137–164.
- 3 Bell K, Cookfair D, Bell D, Reese P, Cooper L (1991). Risk factors associated with chronic fatigue syndrome in a cluster of pediatric cases. Rev Infect Dis. 13(Suppl1): S32–S38.
- 4 Berntsson LT, Köhler L, Gustafsson JE (2001). Psychosomatic complaints in schoolchildren: a Nordic comparison. Scand J Public Health. 29(1): 44–54.
- 5 Blum R (1986). Psychosomatic illness in adolescence. Adv Adolesc Mental Health. 1(Pt A): 119–161.
- 6 Boekaerts M & Roder I (1999). Stress, coping, and adjustment in children with a chronic disease: a review of the literature. *Disabil Rehabil*. 21: 311–337.
- 7 Cadman D, Boyle M. Szatmari P, Offord DR (1987). Chronic illness, disability and mental and social well-being: findings of the Ontario child health study. *Pediatrics*. 79: 805–812.
- 8 Calsbeek H, Rijken M, Bekkers MJ, Kerssens JJ, Dekker J, van Berge Henegouwen GP (2002). Social position of adolescents with chronic digestive disorders. Eur J Gastroenterol Hepatol. 14: 543–549.
- 9 Campo JV, Comer DM, Jansen-Mcwilliams L, Gardner W, Kelleher KJ (2002). Recurrent pain, emotional distress, and health service use in childhood. *J Pediatr.* 141(1): 76–83.
- 10 Carnevale FA (1997). The experience of critically ill children: narratives of unmaking. *Intensive Crit Care Nurs.* **13**(1): 49–52.
- 11 Chavira DA, Garland AF, Daley S, Hough R (2008). The impact of medical comorbidity on mental health and functional health outcomes among children with anxiety disorders. J Dev Behav Pediatr. 29: 394–402.
- 12 Cohen JA (2005). Posttraumatic stress disorder in children and adolescents. In: Sadock BJ, Sadock VA, editors. Kaplan & Sadock's Comprehensive Textbook of Psychiatry. 8<sup>th</sup> ed, vol II. Lippincott Williams & Wilkins, Philadelphia, p. 3286–3291.
- 13 Cohen P, Pine DS, Must A, Kasen S, Brook J (1998). Prospective associations between somatic illness and mental illness from childhood to adulthood. Am J Epidemiol. 147: 232–239.
- 14 Colville G (2008). The psychologic impact on children of admission to intensive care. *Pediatr Clin North Am.* **55**(3): 605–616.
- 15 Colville GA & Pierce CM (2013). Children's self-reported quality of life after intensive care treatment. *Pediatr Crit Care Med.* 14(2): e85–e92.
- 16 Connolly D, McClowry S, Hayman L, Mahony L, Artman M (2004). Posttraumatic stress disorder in children after cardiac surgery. J Pediatr. 144(4): 480–484.
- 17 Dale JK & Straus SE (1992). The chronic fatigue syndrome; considerations relevant to children and adolescents. Adv Pediatric Infect Dis. 7: 63–83.
- 18 Davydow DS, Richardson LP, Zatzick DF, Katon WJ (2010). Psychiatric morbidity in pediatric critical illness survivors: a comprehensive review of the literature. Arch Pediatr Adolesc Med. 164(4): 377–385.
- 19 Domènech-Llaberia E, Jané C, Canals J, Ballespí S, Esparó G, Garralda E (2004). Parental reports of somatic symptoms in preschool children: prevalence and associations in a Spanish sample. J Am Acad Child Adolesc Psychiatry. 43(5): 598–604.
- 20 Drell MJ & White TJH (2005). Children's reaction to illness and hospitalization. In: Sadock BJ, Sadock VA, editors. Kaplan & Sadock's Comprehensive Textbook of Psychiatry. 8<sup>th</sup> ed, vol II. Lippincott Williams & Wilkins, Philadelphia, p. 3425–3434.

- 21 Eiser C (1993). Growing up with chronic disease. The impact on children and their families. Jessica Kingsley, London.
- 22 Eminson DM (2007). Medically unexplained symptoms in children and adolescents. Clin Psychol Rev. 27(7): 855–871.
- 23 Engelen V, Detmar S, Koopman H, Maurice-Stam H, Caron H, Hoogerbrugge P, et al (2012). Reporting health-related quality of life scores to physicians during routine follow-up visits of pediatric oncology patients: is it effective? Pediatr Blood Canc. 58: 766–774.
- 24 EvansDL, Charney DS, Lewis L, Golden RN, Gorman JM, Krishnan KR, et al (2005). Mood disorders in the medically ill: scientific review and recommendations. *Biol Psychiatry*. **58**: 175–189.
- 25 Feder H, Dworkin P, Orkin O (1994). Outcome of 48 pediatric patients with chronic fatigue; a clinical experience. Arch Fam Med. 3: 1049–1055.
- 26 Fink P, Rosendal M, Olesen F (2005). Classification of somatization and functional somatic symptoms in primary care. *Aust N Z J Psychiatry*. **39**(9): 772–781.
- 27 Garralda M (1992). Severe chronic fatigue syndrome in childhood; a discussion of psychopathological mechanisms. *Eur J Child Adolesc Psychiatry*. 1: 111–118.
- 28 Garralda ME & Bailey D (1987). Psychosomatic aspects of children's consultations in primary care. Eur Arch Psychiatry Neurol Sci. 236(5): 319–322.
- 29 Garralda ME & Palance MI (1994). Psychiatric adjustment in children with physical illness. *Br J Hospital Med.* **52**: 230–234.
- 30 Garralda ME, Jameson RA, Reynolds JM, Postlethwaite RJ (1988). Psychiatric adjustment in children with chronic renal failure. J Child Psychol Psychiatry. 29: 79–90.
- 31 Geist R, Weinstein M, Walker L, Campo JV (2008). Medically unexplained symptoms in Young people: the physician's dilemma. *Paediatr Child Health (Oxford)*. **13**(6): 487–491.
- 32 Gieteling MJ, Lisman-van Leeuwen Y, van der Wouden JC, Schellevis FG, Berger MY (2011). Childhood nonspecific abdominal pain in family practice: incidence, associated factors, and management. *Ann Fam Med.* **9**(4): 337–343.
- 33 Gledhil J & Garralda ME (2009). The relationship between physical and mental health in children and adolescents. In: Gelder MG, Andreasen NC, López-Ibor J, Geddes JR, editors. New Oxford Textbook of Psychiatry, vol. 2, Oxford University Press, Oxford, p. 1740–1747.
- 34 Goodwin RD, Fergusson DM, Horwood LJ (2004). Asthma and depressive and anxiety disorders among young persons in the community. *Psychol Med.* **34**: 1465–1474.
- 35 Griffith JL & Slovik L (2008). Family therapy. In: Tasman A, Kay J, Lieberman JA, First MB, Maj M, editors. Psychiatry, 3<sup>rd</sup> ed., vol. 2. John Willey and Sons, Ltd, Chichester, p. 1948–1962.
- 36 Hallum A (1995). Disability and the transition to adulthood: issues for the disabled child, the family, and the pediatrician. *Curr Probl Pediatr.* **25**: 12–50.
- 37 Hammad TA, Laughren T, Racoosin J (2006). Suicidality in pediatric patients treated with antidepressant drugs. Arch Gen Psychiatry. 63: 332–339.
- 38 Hartman A, DePoy E, Francis C, Gilmer D (2000). Adolescents with special health care needs in transition: three life histories. Soc Work Health Care. 31: 43–57.
- 39 Haverman L, Engelen V, van Rossum MA, Heymans HS, Grootenhuis MA (2011). Monitoring health-related quality of life in paediatric practice: development of an innovative web-based application. *BMC Pediatrics.* **11**: 3.
- 40 Haverman L, van Rossum MA, van Veenendaal M, van den Berg JM, Dolman KM, Swart J, et al (2013). Effectiveness of a webbased application to monitor health-related quality of life. *Pediatrics*. **131**: e533–e543.
- 41 Heru A (2006). Family psychiatry: from research to practice. Am J Psychiatry. **163**: 962–968.
- 42 Immelt S (2006). Psychological adjustment in young children with chronic medical conditions. J Pediatr Nurs. 21(5): 362–377.
- 43 Jayshree M, Singhi SC, Malhi P (2003). Follow-up of survival and quality of life in children after intensive care. *Indian Pediatr.* **40**(4): 303–309.
- 44 Judge D, Nadel S, Vergnaud S, Garralda ME (2002). Psychiatric adjustment following meningococcal disease treated on a PICU. *Intensive Care Med.* 28(5): 648–650.

- 45 Katon W, Lin E, Von Korff M, Russo J, Lipscomb P, Bush T (1991). Somatization: a spectrum of severity. *Am J Psychiatry*. **148**(1): 34–40.
- 46 Kazak AE, Alderfer M, Rourke MT, Simms S, Streisand R, Grossman JR (2004) . Posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in families of adolescent childhood cancer survivors. *J Pediatr Psychol.* 29: 211–219.
- 47 Knoester H, Grootenhuis MA, Bos AP (2007). Outcome of paediatric intensive care survivors. Eur J Pediatr. 166(11): 1119–1128.
- 48 Kovacs M, Feinberg TL, Paulauskas S, Finkelstein R, Pollock M, Crouse-Novak M (1985). Initial coping responses and psychosocial characteristics of children with insulin-dependent diabetes mellitus. J Pediatr. 106: 827–834.
- 49 Law M, King G, King S, Kertoy M, Hurley P, Rosenbaum P, et al (2006). Patterns of participation in recreational and leisure activities among children with complex physical disabilities. Dev Med Child Neurol. 48: 337–342.
- 50 Lederberg MS (2005). Psychooncology. In: Sadock BJ, Sadock VA, editors. Kaplan & Sadock's Comprehensive Textbook of Psychiatry. 8<sup>th</sup> ed, vol II. Lippincott Williams & Wilkins, Philadelphia, p. 2196–2225.
- 51 Lindley KJ, Glaser D, Milla PJ (2005). Consumerism in healthcare can be detrimental to child health: lessons from children with functional abdominal pain. Arch Dis Child. 90(4): 335–337.
- 52 Lindsay S (2011). Employment status and work characteristics among adolescents with disabilities. *Disabil Rehabil*. **33**: 843–854
- 53 Liss DS, Waller DA, Kennard BD, McIntire D, Capra P, Stephens J (1998). Psychiatric illness and family support in children and adolescents with diabetic ketoacidosis: a controlled study. J Am Acad Child Adolesc Psychiatry. 37: 536–544.
- 54 Logan DE, Williams ŚE, Carúllo VP, Claar RL, Bruehl S, Berde CB (2013). Children and adolescents with complex regional pain syndrome: more psychologically distressed than other children in pain? *Pain Res Manag.* **18**(2): 87–93.
- 55 Maslow GR, Haydon A, McRee AL, Ford CA, Halpern CT (2011). Growing up with a chronic illness: social success, educational/vocational distress. J Adolesc Health. 49: 206–212.
- 56 Merikangas KR, Nakamura EF, Kessler RC (2009). Epidemiology of mental disorders in children and adolescents. *Dialogues Clin Neurosci.* 11: 7–20.
- 57 Parry-Langdon N, Clements A, Fletcher D, Goodman R (2008). Three Years On Survey Of the Development and Emotional Well-Being of Children and Young People. Newport, UK: Office for National Statistics.
- 58 Perrin JM, Bloom SR, Gortmaker SL (2007). The increase of child-hood chronic conditions in the United States. JAMA. 297: 2755–2759.
- 59 Pipe R & Wait M (1995). Family therapy in the treatment of chronic fatigue syndrome in adolescence. ACPP Rev Newsletter. 17: 9–16.
- 60 Pless IB, Cripps HA, Davies JMC, Wadsworth ME (1989). Chronic physical illness in childhood: psychological and social effects in adolescence and adult life. Dev Med Child Neurol. 31: 746–755.
- 61 Poggi G, Liscio M, Galbiati S, Adduci A, Massimino M, Gandola L, et al (2005). Brain tumors in children and adolescents: cognitive and psychological disorders at different ages. Psychooncology. 14: 386–395.
- 62 Price JR & Couper J (1998). Cognitive behavior therapy for adults with chronic fatigue syndrome. Cochrane Review, the latest version: August 1998. In: The Cochrane Library. Oxford, England.
- 63 Rask CU (2012). Functional somatic symptoms in 5–7 year old children: assessment, prevalence, and co-occurrence. *Dan Med J.* 59(11): B4537.
- 64 Rask CU, Olsen EM, Elberling H, Christensen MF, Ornbøl E, Fink P, et al (2009). Functional somatic symptoms and associated impairment in 5-7-year-old children: the Copenhagen Child Cohort 2000. Eur J Epidemiol. **24**(10): 625–634.
- 65 Raz A (2006). Perspectives on the efficacy of antidepressants for child and adolescent depression. *PloS Med.* **3**: 9.
- 66 Rees G, Gledhill J, Garralda ME, Nadel S (2004). Psychiatric outcome following paediatric intensive care unit (PICU) admission: a cohort study. *Intensive Care Med.* 30(8): 1607–1614.

- 67 Rennick JE & Rashotte J (2009). Psychological outcomes in children following pediatric intensive care unit hospitalization: a systematic review of the research. *J Child Health Care.* **13**(2): 128–149.
- 68 Rennick JE, Dougherty G, Chambers C, Stremler R, Childerhose JE, Stack DM, *et al* (2014). Children's psychological and behavioral responses following pediatric intensive care unit hospitalization: the caring intensively study. *BMC Pediatrics*. **14**: 276. doi: 10.1186/1471-2431-14-276.
- 69 Rennick JE, Johnston CC, Dougherty G, Platt R, Ritchie JA (2002). Children's psychological responses after critical illness and exposure to invasive technology. J Dev Behav Pediatr. 23(3): 133–144.
- 70 Rikard-Bell CJ & Waters BG (1992). Psychosocial management of chronic fatigue syndrome in adolescence. *Aust NZ J Psychiatry*. **26**: 64–72.
- 71 Rutter M, Tizard J, Whitmore K, editors (1970). Education, health, and behavior. Longmans, London.
- 72 Schell A, Albers L, von Kries R, Hillenbrand C, Hennemann T (2015). Preventing Behavioral Disorders via Supporting Social and Emotional Competence at Preschool Age. *Dtsch Arztebl Int.* **112**(39): 647–654.
- 73 Sidebotham P, Skeldon I, Chambers T, Clements S, Culling J (1994). Refractory chronic fatigue syndrome in adolescence. Br J Hosp Med. 51: 110–112.
- 74 Stam H, Grootenhuis MA, Last BF (2005). The course of life of survivors of childhood cancer. *Psychooncology*. **14**: 227–238.
- 75 Stam H, Hartman EE, Deurloo JA, Groothoff J, Grootenhuis MA (2006). Young adult patients with a history of pediatric disease: impact on course of life and transition into adulthood. *J Adolesc Health.* 39: 4–13.
- 76 Stewart SM, Rao U, White P (2005). Depression and diabetes in children and adolescents. *Curr Opin Pediatr.* **17**: 626–631.
- 77 Stone M, Laughren T, Jones ML, Levenson M, Holland PC, Hughes A, et al (2009). Risk of suicidality in clinical trials of antidepressants in adults: analysis of proprietary data submitted to US Food and Drug Administration. BMJ. **339**: b2880.
- 78 Strine TW, Okoro CA, McGuire LC, Balluz LS (2006). The associations among childhood headaches, emotional and behavioral difficulties, and health care use. *Pediatrics*. 117(5): 1728–1735.
- 79 Surawy C, Hackmann A, Hawton K, Sharpe M (1995). Chronic fatigue syndrome: a cognitive approach. *Behav Res Ther.* **33**(5): 535–544.
- 80 Taveras EM, Gillman MW, Peña MM, Redline S, Rifas-Shiman SL (2014). Chronic sleep curtailment and adiposity. *Pediatrics*. **133**(6): 1013–1022.
- 81 Taylor A, Butt W, Ciardulli M (2003). The functional outcome and quality of life of children after admission to an intensive care unit. *Intensive Care Med.* **29**(5): 795–800.
- 82 van de Loo KF, van Dongen L, Mohamed M, Gardeitchik T, Kouwenberg TW, Wortmann SB, et al (2013). Socio-emotional problems in children with CDG. JIMD Rep. 11: 139–148.
- 83 Vereker M (1992). Chronic fatigue syndrome: a joint paediatric-psychiatric approach. *Arch Dis Child*. **67**: 550–555.
- 84 Verhoof E, Maurice-Stam H, Heymans H, Grootenhuis M (2012). Growing into disability benefits? Psychosocial course of life of young adults with a chronic somatic disease or disability. *Acta Paediatr.* **101**: e19–e26.
- 85 Verhoof EJ, Maurice-Stam H, Heymans HS, Evers AW, Grootenhuis MA (2014). Psychosocial well-being in young adults with chronic illness since childhood: the role of illness cognitions. *Child Adolesc Psychiatry Ment Health.* **8**: 12.
- 86 Wachsmuth J & MacMillan H (1991). Effective treatment for an adolescent with chronic fatigue syndrome. Clin Pediatrics. 30: 488–490.
- 87 Wass VJ, Barratt TM, Horwath RV, Marshall WA, Chantler C, Ogg CS, et al (1977). Home dialysis in children. Lancet. 1: 2426.
- 88 Wessely S, Hotopf M, Sharpe M (1999). Chronic Fatigue and its Syndromes. Oxford University Press, Oxford.
- 89 Wohlfarth T, Kalverdijk L, Rademarker C, Schothorst P, Minderaa R, Gispende Wied C (2009). Psychopharmacology for children: from off-label use to registration. *Eur Neuropsychopharmacol.* **19**: 603–608.