



Editor's Comment

Ever-expanding medical knowledge and technical advances have enabled many children and adolescents with chronic medical conditions to look forward to living longer and enjoying a better quality of life. Mental health professionals are being increasingly called upon to help children and their families deal with the psychological and social aspects of chronic medical illness. In this *NYU Child Study Center Letter* we discuss the issues critical to understanding the psychology of chronic medical illness – definitions and prevalence, models for understanding the interaction of illness and psychological adjustment, psychological risk factors, causes of adjustment problems and psychological disorders as well as strategies of prevention and intervention. Understanding the interaction of the medical illness and psychological factors can form the basis of an intervention plan that can affect the course and outcome of the illness and maximize the well-being of a child with chronic medical illness.

HSK

Introduction

Both children and adults with medical illnesses have benefited from twentieth century advances in medicine, and clearly still more advances loom on the horizon of this century. Children who, in the past, might have died or had their physical functioning severely comprised by their illness are now living into adulthood. As more children survive childhood diseases they have a potentially better quality of life than ever before. The leading consequence is that attending to children's physical care also requires attending to their psychological well-being. Mental health professionals have been increasingly sought out by families and physicians to help chronically ill children and their families with illness-related problems optimize psychological functioning throughout life.

CHILDREN WITH A CHRONIC ILLNESS: THE INTERFACE OF MEDICINE AND MENTAL HEALTH

Definition and prevalence

Although any individual childhood illness is rare, and each has its own prevalence, it is estimated that up to 20% of the school-age population has a chronic medical illness or disabling condition, putting the number of children under age eighteen with chronic conditions at twelve million.¹ Chronic illness has been defined as, "a disorder with a protracted course that can be fatal or associated with a relatively normal life span despite impaired physical or mental functioning. Such an illness frequently shows a period of acute exacerbations requiring intensive medical attention."² Chronic illness or disease differs from acute illness in that, (1) it is treatable yet not curable, thus needs management for long periods of time, and therefore, (2) the responsibility for the management of the illness is shared with and/or transferred to the child and family.³ Illnesses such as asthma, insulin dependent diabetes mellitus (IDDM), congenital heart disease, juvenile rheumatoid arthritis, sickle cell disease, hemophilia, cystic fibrosis, cancer, and AIDS fit this definition of chronic illness. Although these conditions have distinct biological processes, there are numerous commonalities with respect to the psychosocial impact on the child.

Psychological risk factors related to illness

The coping ability and adjustment of the chronically ill child or adolescent depend on multiple factors. These include risk factors related to the illness itself and resistance factors related to the individual.⁴ Although there is no one-to-one

relationship between any particular risk factor and a particular outcome, the areas of influence include:

- **the degree to which the illness impairs functioning:** functional disability seems to increase the risk of psychological problems, but the relationship is complicated by other factors. For example, it has been suggested that visibility of illness may contribute to improved psychological functioning because the inability to hide or deny the condition may compel the child to adjust and accept his status;⁵
- **involvement of the brain:** behavior, social and cognitive problems have been consistently associated with conditions or treatments affecting the brain.⁶ In some instances, insults to the brain, as when a stroke or tumor occurs, can lead to impairments in cognitive functioning that can cause learning problems or social skills deficits;
- **the nature of the illness:** the severity and the course of the illness, and the direct threat to life influence psychological concerns and outcome. For example, cystic fibrosis impairs lung functioning and decreases later life expectancy. Thus, fear of death may increase over time in concert with the change in illness status. For a child with cancer, in spite of a possible 70-90% rate of remission for some forms of cancer, the terror of death at diagnosis is more likely to occur than for someone diagnosed with IDDM;
- **the type of medical procedures and hospital/non-hospital required experience:** direct interventions – painful or benign – and where they occur vary



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widely. Sickle cell disease may require ongoing lifestyle changes with intermittent hospital admission for painful crises. This illness biography impacts a child differently than a lifetime routine of self-administered insulin injections by a child with IDDM or the surgery and concentrated 14-month treatment for a child with bone cancer;

- **the interference with non-illness related aspects of life:** an illness can easily spill over into or consume other areas of life. A child with acute lymphocytic leukemia may need chemotherapy and related treatment for three years. This treatment necessitates sporadic school absence that is likely to affect social and academic skills development. These academic and social risks are different than those for the child with juvenile arthritis, for example, who must have a modified school athletic program;
- **family functioning:** both the way the family functions and the effect of the illness on the family influence the child. Parents, siblings, grandparents, and extended family members are prone to particular expected reactions to illness that in turn impact the child. Parents' emotional well-being and style of coping directly affect the child, either due to the child's modeling of parents' reactions, or because the parents' functioning changes the family environment. Marital stress and family functioning can be either helped or hurt when a child has a chronic illness, but illness alone does not automatically cause long lasting family trauma. The consensus is that a child does best when a family is cohesive, flexible, supportive, the mother is coping well, and communication is open and clear;⁷
- **the individual characteristics and internal resources of the child:** pre-illness personality, functioning, and coping ability interact with the illness-related situation to affect the level of distress for the child. Anxiety and learning disorders, attention-deficit/hyperactivity disorder, etc., exist in the general population as does poor family functioning, abuse and neglect—all of which can be components in the child's life irrespective of, but affecting, the illness picture. Unfortunately, most findings in this area are gathered after an illness, making preventive conclusions difficult;

- **demographic variables such as age, sex, social class:** the general influence of non-illness risk factors also have bearing on adjustment, psychiatric, or behavioral problems. For example, "the risk of emotional problems in the general population increases with age, the emotional well being of boys with a chronic physical illness is usually more affected than girls," but not always, and the risk is greater for those with a chronic illness as well as a disability;⁸
- **external resources and support systems:** adequate outside support can have a positive effect on the child and family's adjustment and is related to personal, financial and geographic factors. Social support typically includes available interpersonal networks and is seen as either protecting individuals from the detrimental affects of stressful life events or enhancing life regardless of life stress. There is also a dynamic interaction between the individual and the actual supports. However, the individual's perception or interpretation of the availability, size, and utility of these systems or individuals influences their effectiveness.⁹ An at-home single mother with more than one child may require and accept different kinds of help than a working couple with one child, newly relocated to another part of the country and feeling distant from family. Therefore providing support requires an understanding of an individual's preferred style, what is deemed supportive, and how it is most successfully accessed.

Incidence and cause of psychosocial adjustment problems and psychiatric disorders

The general consensus of the limited literature is that chronically ill children are at risk for psychological problems. There is, however, little agreement as to the incidence or cause. Estimates range from 9-37%, compared to 5-15% in the general population.¹⁰ Problems that do exist are most likely a normal response to illness-related issues and experiences rather than an indication of serious disturbance.¹¹ This is not to say their significance should be ignored, only that they should be put in the correct context.

Definitive epidemiological statistics and results of intervention programs are difficult to report due to: existing resistance or denial of the problem from medical staff, the small numbers of children available with any one illness, the flaws inherent in collecting data from children with different illnesses, the lack of adequate comparative control groups, and the problem in accurately defining appropriate adjustment for these children. Because chronic illness itself is not likely to cause serious psychiatric disturbance, distinguishing between symptoms characteristic of a more systemic problem, such as depression or anxiety, and those resulting from the illness and situation, such as the stress of hospitalization or separation from parents, is of key importance.¹²

It is not unusual for children hospitalized for long periods of time to develop sleep, eating, or behavior problems due to constant waking by staff, physical restriction from intravenous lines, unappealing food, and to experience feelings of frustration and lack of control. A 5-year-old girl with a brain tumor may tantrum due to anxiety about being separated from her parents while receiving radiation treatments. These situations are instances of reactions precipitated by particular illness-related events. On the other hand, a pre-adolescent with hemophilia may be non-compliant with medical appointments and guidelines for curtailed physical activity as a result of conduct or learning problems unrelated to, but interfering with, the illness.

The most common psychological problems and areas of concern for mental health professionals are:

- **internalizing problems:** anxiety, depression, fear, hopelessness, helplessness, loss of control, frustration
- **externalizing problems:** aggression, noncompliance, withdrawal
- **somatic complaints:** pain and impaired functioning
- **self-concept issues:** poor self-image, low self-esteem, changed or negative identity
- **social and educational difficulties:** academic and learning problems, decreased or deficient social competence

Particular problems that vary by illness are associated across different illnesses but for different reasons. For example, cognitive deficits are a possible complication

for children with leukemia who have had cranial radiation and for children with sickle cell disease if they have had strokes. As medicine and mental health services help more children, more are physically and emotionally healthier. A review of 60 studies of children ages 4-18 who had various chronic medical problems concluded that children with cancer were no more depressed than other children.¹³ Thus outcome research may show even smaller differences and more accurately delineate etiology and identify successful treatment. In fact most recently, cancer patient survivors were found to be functioning as well as, if not better than, their healthy counterparts on measures of aggression, anti-social behavior, and substance abuse.¹⁴

Models for understanding the interaction of illness and adjustment

Various models have been proposed for explaining and directing research on psychosocial adjustment, but most are generally constructed around concepts of stress and coping. Different theoretical frameworks describe the source of stress as:¹⁵

- emanating from the illness itself, as when a child with asthma has a flair-up of breathing problems or must be hospitalized for a procedure; or from life stress and the environment, such as when a child changes schools or has parents who are divorcing;
- derived from the interaction between specific illness risk factors (e.g. functional handicap and existing mental health problems) and protective or resistance factors (e.g. parental adjustment and problem solving ability).

One way to understand adjustment is by looking at the relationship between the source of the stress or threat and an individual's personal appraisal of stress. The basic stress and coping model posits that stress can be objective (e.g. shots hurt) or subjective (e.g. being afraid of shots). Successful coping strategies can be either problem-focused, addressing the objective source, or emotion-focused, directed at the subjective affective response.¹⁶ Active problem-focused coping efforts on the part of the child have proven to be more effective than avoidant coping or self-blame for concrete illness-related medical needs.¹⁷

Research has yet to tailor treatment protocols due to an incomplete understanding of variables that influence treatment outcome. Age, gender, cognitive ability, and personality style are some factors that have been shown to independently or interdependently act on illness to impact outcome. For example, one study showed that girls with migraine headaches "profited more from [behavioral-psychophysiological treatment] than boys, and those with a shorter history of migraine evidenced greater headache reduction as a result of treatment."¹⁸ Also unclear are the processes responsible for change. For example, a family-based intervention has been shown to improve metabolic control of adolescents with diabetes but not family functioning, so the family-specific mechanism responsible for the change is not apparent. Thus successful functioning is dependent on isolating salient variables which affect treatment outcomes and refining interventions.¹⁹

Management of illness-related issues: Prevention and intervention

Due to the variability in illness type, degree of physical impairment, and the individual characteristics of the child's situation, identifying interventions requires careful assessment. Ideally, even though an understanding of the psychological issues is reached according to their medical origin, particular consideration should also be given to the individual and family variables that will influence intervention outcome.

The medical model for understanding illness prevails when a child's problems originate from a medical illness and the case is identified via the medical system. Prescribing an intervention can best be done by understanding the concrete medical/ illness basis for the problem and its consequent psychological problem. For example, a child on chemotherapy with periodic low white blood cell counts may have restricted social activities. Psychologically, the child can feel he has no control over his body or illness, feel isolated, and therefore be angry and withdrawn. Intervention must target the source of the problem (perhaps with education or instruction on infection precautions) in addition to the resulting feelings and behaviors (perhaps by encouraging viable options for maintaining contact with classmates).

When, why, and how to intervene

Planning an intervention is a complex process. The first step is to decide on a target problem and which aspect of the problem to attack.²⁰ At first glance, a problem may seem straightforward, yet closer inspection usually reveals the interconnected, multi-determined nature of medically-related psychosocial problems. For example, fluctuating insulin levels in a child with IDDM are most obviously related to inadequate insulin management. The cause of the poor management, however, is less obvious. Possible explanations include: improper technique, poor understanding of the disease, lack of parental supervision of a child who is self-administering insulin, and a child or parent's anger or denial.

The goals of preventive and targeted intervention include:

1. "mastery of anxiety and fears related to the illness and its management;
2. a developmentally appropriate understanding of the illness;
3. compliance with treatment regimens;
4. integration of the illness into family life, including a balance between the needs of other family members;
5. successful adaptation to the important systems, such as the hospital, school and peers."²¹

Types of interventions

Various interventions have been used with the child and/or those individuals in the home or school environments to meet the psychological demands imposed by the illness. Listed below are some of the most prevalent interventions.

Education: The importance of education about a disease – its cause, course, treatment, and long term effects – is often overlooked. But understanding of this information is influenced by the patient's age, cognitive ability, and psychological style. Children, like adults, vary as to the amount and type of information that is useful. Educating a child and family is not an all-or-nothing, single event. Accurate, honest information is the standard, but it must be transmitted in language appropriate to a child's age, when he/she is ready, and perhaps repeated at different times and in different formats. This also means refraining from making unrealistic pro-

mises such as "this won't hurt." A long-term view of education is also important. It is incorrect to assume that a child diagnosed with leukemia at 3 years of age, treated until age 6, who has relapsed at age 8 will know all there is to know based on experience alone. Misconceptions and inadequate and inaccurate information likely coexist and are confused with a more mature conceptualization. As children age, new issues become relevant. Genetic concerns with respect to marriage and pregnancy, for example, may emerge for the young adult with cystic fibrosis who is exploring intimate relationships. Education about appropriate parent-child interactions can decrease parents' over-protective tendencies and the child's adoption of the "sick" role. Illness information and guidance about interacting with the health care system and staff also can empower children and parents to be useful advocates and care partners.

Cognitive-behavioral strategies: Cognitive and behavioral techniques can help a child or teen identify the source of stress, change how it is perceived, and/or teach new behaviors. The goal of this approach is to reduce the impact of the stress, and to change feelings and consequent experiences. Cognitive components can include exploration of the link between thoughts and actions and training in more helpful ways of thinking about problems or symptoms. Behavioral components can include: breathing exercises, filmed modeling, systematic desensitization, behavioral rehearsal, positive reinforcement, distraction, and hypnosis-related techniques such as progressive muscle relaxation, focused attention and guided imagery. Play and art can also be utilized to improve mastery of medically-related behaviors or in conjunction with role play, imagery and relaxation strategies. Rehearsing bone marrow aspirations or teaching self-injection for IDDM via realistic dolls can gradually improve technique, shape compliance, and decrease fear.

Social skills training: Given that problematic peer relations can impact later psychosocial development, improving social functioning can have a protective effect. Interpersonal skill deficits can result from (1) lack of specific abilities, (2) lack of opportunity, or (3) emotional or cognitive factors that interfere with performance.²² Effective training can result in improved self-esteem, confidence, and so-

cial competence. The components of social skills training programs vary, but typically should involve:

- behavioral training: this can include modeling, rehearsal, corrective feedback, and reinforcement
- skill instruction: direction and teaching for specific skills such as starting conversations, joining games, increasing peer acceptance
- problem-solving: skill training has been shown to be enhanced by training the cognitive processes needed for implementing learned skills. Teaching a child to learn to assess, negotiate, and plan action in social situations improves implementation and generalizability of skills.²³

Remediation and rehabilitation:

Physical and academic remediation and rehabilitation for functional deficits can have a tremendous impact on psychological functioning. Early intervention in these areas allows children to be active, rather than passive participants in their illness management, and provides concrete, sequential feedback of improvement. Both the concrete progress and inherent message communicated by remediation and rehabilitation can counterbalance feelings of helplessness and hopelessness that often result from the vague, slow, long-term, sometimes static trajectory of medical improvement.

Family therapy and group work:

Given the interactive relationship between the child's illness and family and friends, working within a larger context can be helpful. Family work is often included in the management of the chronic illness with life-long duration, such as asthma and diabetes, where the family members can exert a positive effect on illness management. It can also be helpful for ventilation of feelings and clarification of misinformation by children and their siblings. Illness-related groups for children and adolescents with either similar or mixed illnesses can offer support through reality testing and shared problem solving. Going one step further, interventions done in school with respect to school re-entry or socialization can be considered as group work. A child's social skills can be enhanced when work done individually is augmented with work done in the actual setting with peers. Providing guidance for handling school absence, physical difference, or answering questions can ease or eliminate teasing or isolation and improve peer relations.^{24, 25}

Examples of implementation

The following two areas of concern typify issues that present to mental health professionals. The issue of school re-entry illustrates the use of intervention to minimize the immediate school-related problems secondary to a chronic illness and the prevention of later social and academic problems. Pain management represents a common acute problem, which if inadequately treated, can complicate medical treatment and lead to future adjustment and psychological difficulties.

School integration or re-entry: In easing the integration or return to school for the chronically ill child most efforts focus on all fronts: assisting the staff, classmates, and the child. The staff is helped by being educated about the illness and any necessary modifications that need to be made, such as a shortened day, restriction of foods or activities, and possible academic difficulties. The staff should also be guided as to how to explain the child's illness to the class.

Consideration should be given to what the child and family want shared, what vocabulary to use, and if and how the child wants to participate in any teaching or transmitting of information. School staff should also be alerted to possible problem areas, such as upcoming treatments that could interfere with a standardized testing timetable, or a hospital admission that will prevent attendance at an important school dance. Academic concerns should be identified; either those that predate the illness or are newly caused by the illness. The child herself can be helped before returning to school by learning and practicing strategies to help her deal with potentially awkward peer interactions. Problem solving, role playing (perhaps related to explanations about the illness), and assertiveness training for possible teasing can be helpful.²⁶ Having staff and/or the child talk directly to peers and having a child present a healthy and positive attitude can demystify misconceptions and increase acceptance.

Pain management: Given that pain is multi-determined, resulting from the interaction of physical and psychological components, interventions focus on two areas. Pain perception is addressed by teaching the child, 1) "to regulate or modify his or her perception of pain through self-regulatory methods such as hypnosis, guided imagery, relaxation, and biofeedback," and, 2) improving pain behavior through "the manipulation and modification of environmental events that maintain pain behaviors."²⁷ Assessment of a child who is referred for pain management entails gathering information from observers – parents, medical staff – as well as from the child. The child might be asked to describe the pain and to rate it by means of an objective scale. Unrealistic information and fears might need to be addressed and corrected through education. Other helpful strategies to develop a revised stress and coping cycle might include: relaxation techniques to train a new response when pain starts; doll play to help the child localize the pain, externalize feelings, and practice positive coping strategies; and self-hypnosis using patient-generated guided imagery. The parents can be educated about expected levels of pain to prevent them from overreacting to their child's pain and they may be enlisted as coaches to assist the child in following through with a particular regimen of pain control. Decreased pain and anticipatory anxiety, increased sense of control and mastery, and enhanced ability to engage in normal activities resulting in prevention of later social sequelae would indicate success.

Outlook for the future

The physical and psychological future for children and teens with chronic illness appears brighter than ever. With attention to their emotional needs, targeted interventions with a mental health professional, and guidance to parents, children's adjustment and quality of life can be maximized. While awaiting medical cures or undergoing existing treatments, mental health care can help children and teens feel confident, effectively manage stress, adapt to their particular illness and grow to be independent, socially competent adults.

About the author

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Related books on medical illness for children (some of many):

Ages 4-8

Krisher, T (1992) Kathy's Hats. Concept Books

Mills, JC (1998) Little Tree: A Story for Children with Serious Medical Problems. Magination Press

Ages 9-12

Ward-Wimmer, D & Hershfield, B (1999) Because...Somebody Loves Me. Child Welfare League of America

Ages 13 and older

Gunther, J (1998) Death Be Not Proud: A Memoir. Harperperennial Library

Sparks, B (1994) It Happened to Nancy. Flare

AboutOurKids related articles

About Anxiety Disorders
http://www.aboutourkids.org/articles/about_anxiety.html

About Depressive Disorders
http://www.aboutourkids.org/articles/about_depressive.html

About Learning Disorders
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About Posttraumatic Stress Disorder
http://www.aboutourkids.org/articles/about_ptsd.html

Coping With Trauma
<http://www.aboutourkids.org/articles/copingtrauma.html>

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