

**PRACTICE PARAMETER FOR THE PSYCHIATRIC ASSESSMENT AND  
MANAGEMENT OF PHYSICALLY ILL CHILDREN AND ADOLESCENTS**

**ABSTRACT**

This practice parameter describes the psychiatric assessment and management of physically ill children and adolescents. It reviews the epidemiology, clinical presentation, assessment and treatment of psychiatric symptoms in children and adolescents with physical illnesses, and environmental and social influences that can affect patient outcome. **Key Words:** physical illness, children, adolescents, family, consultation, psychosomatic, pediatric.

**ATTRIBUTION**

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AACAP practice parameters are developed by the AACAP Work Group on Quality Issues (WGQI) in accordance with American Medical Association policy. Parameter development is an iterative process between the primary author(s), the WGQI, topic experts, and representatives from multiple constituent groups, including the AACAP membership, relevant AACAP components, the AACAP Assembly of Regional Organizations, and the AACAP Council. Details of the parameter development process can be accessed on the AACAP Web site. Responsibility for parameter content rests with the author(s), the WGQI, the WGQI Consensus Group, and the AACAP Council.

The AACAP develops both patient-oriented and clinician-oriented practice parameters. Patient-oriented parameters provide recommendations to guide clinicians toward best treatment practices. Recommendations are based on empirical evidence (when available) and clinical consensus (when not) and are graded according to the strength of the empirical and clinical support. Clinician-oriented parameters provide clinicians with the information (stated as principles) needed to develop practice-based skills. Although empirical evidence may be available to support certain principles, principles are primarily based on expert opinion derived from clinical experience. This parameter is a clinician-oriented parameter.

The primary intended audience for AACAP practice parameters is child and adolescent psychiatrists; however, the information contained therein may also be useful for other mental health clinicians.

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### INTRODUCTION

Children and adolescents face a wide variety of physical illnesses that may impinge on their development and their emotional, cognitive, behavioral, and social functioning. Illnesses can range from acute acquired conditions to chronic congenital disorders. The direct physical effects of an illness, as well as the resultant emotional and behavioral responses, may last hours to days to months to years. The ramifications of physical illnesses affect not only a child or adolescent, but also parents, significant caregivers, siblings, relatives, friends, and teachers.

The objective of this clinician-oriented parameter is to provide an introduction to the knowledge and skills that are important prerequisites for the effective psychiatric assessment and management of physically ill children and adolescents. The principles stated herein are applicable to the assessment and management of patients aged 18 and younger. In this parameter the term *child* refers to both adolescents and younger children unless explicitly noted. Unless otherwise noted, *parents* refers to the child's primary caretakers, regardless of whether they are the biological or adoptive parents or legal guardians. This document presumes familiarity with normal child development and the principles of child psychiatric diagnosis and treatment and is addressed to any mental health clinician or medical professional who treats a physically ill child.

### METHODOLOGY

The literature review included bibliographies of books, book chapters and review articles, and consultations with clinicians and researchers with specific expertise in this area. *PubMed* and *PsycINFO* searches used the following text words: *physically ill*, *children*, *adolescents*, *pediatric*, *consultation*, and *psychosomatic*. The searches covered the period 1986–2006 and yielded approximately 275 articles, of which only the most relevant are included in this document.

### BACKGROUND

### EPIDEMIOLOGY

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Between 10 and 20 million American children are estimated to have an ongoing physical health condition.<sup>1</sup> While most of these conditions are relatively mild and interfere little with a child's usual activities, at least 10% of children with physical illness have symptoms severe enough to impact their daily lives.<sup>1</sup> Advances in the treatment of physical illnesses over the past few decades have resulted in improved health and prognosis. Whereas many youngsters previously died from severe physical illnesses, greater than 90% now survive into adulthood.<sup>2</sup>

Children and their families are remarkably resilient in adapting to the challenges of a physical condition. The majority of physically ill children do not have identifiable emotional, behavioral, or educational difficulties.<sup>3</sup> While the majority of children with a chronic physical illness do not suffer from a major psychiatric disturbance, the overall risk of psychiatric disorder is somewhat greater than that in the general population of healthy children.<sup>1</sup> Evidence suggests that psychiatric problems in children with chronic physical illnesses present primarily as internalizing syndromes and persist over time.<sup>4-6</sup>

Psychiatric disorders in physically ill children can be conceptually organized by the perceived relationship between the comorbid psychiatric and general medical conditions. See Shaw and DeMaso<sup>7(pp7-10)</sup> for a review. Coincidental comorbidity describes patients with seemingly unrelated psychiatric and physical illnesses, whereas causal comorbidity refers to instances in which the psychiatric disorder is considered to be a direct result of the physical illness (somatopsychic disorders), as might be seen in a child with hyperthyroidism who otherwise meets criteria for an anxiety disorder, or the physical symptoms are attributed to the psychiatric illness (psychosomatic disorders), as represented by an adolescent with functional abdominal pain and an associated generalized anxiety disorder (see Table 1). It must nevertheless be acknowledged that such attributions are rooted in a false dualism and that the relationship between disorders conceptualized as "psychiatric" and "physical" is often indeterminate or bidirectional.

Contrary to expectations, physical illness severity does not appear to play a significant role in adjustment and vulnerability to psychiatric disorder, although the type of physical illness does appear to matter. Numerous studies have found that among conditions that do not involve the brain (e.g., cystic fibrosis, diabetes mellitus, or asthma), there is no relationship between disease severity and psychosocial adjustment.<sup>7-10</sup> By contrast, youngsters with illnesses that affect the central nervous system (e.g., epilepsy, cerebral palsy) have an increased risk for psychiatric disorder.<sup>11,12</sup> Adolescents with multiple chronic physical conditions<sup>13</sup> and/or long-term physical disability also appear to be at higher risk for psychological problems.<sup>14</sup>

There is evidence that a child's psychiatric illness may affect the physical disease process, not only by influencing adherence and lifestyle, but also by producing psychophysiological changes. For instance, youngsters with diabetes mellitus not only have been found to be at risk for depressive disorders,<sup>15</sup> but those who have comorbid depression are at increased risk for treatment nonadherence and repeated hospitalization<sup>16</sup> as well as disease-related complications (e.g., diabetic retinopathy).<sup>17</sup> Depressive symptoms have been found to be common and associated with worsening asthma symptoms in inner-city children,<sup>18</sup> while a negative family emotional climate contributes to a child's depressive symptoms, which in turn contribute to asthma disease severity.<sup>19</sup>

### CONCEPTUALIZATION OF THE ILLNESS EXPERIENCE

Two common approaches have been used to conceptualize the childhood physical illness experience: diagnosis-specific and noncategorical.<sup>1,2,20,21</sup> The diagnosis-specific approach

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considers the illness experience in the context of specific diseases. For example, studies in asthma, diabetes, and patients with recurrent abdominal pain suggest psychological symptoms and patterns of behavior that are disease-specific and warrant consideration when planning treatment and judging prognosis.<sup>22-24</sup>

The noncategorical approach, by contrast, considers the illness experience in the context of general dimensions (e.g., visible/invisible, fatal/nonfatal, stable/unpredictable) that pertain to illness irrespective of specific disease.<sup>20</sup> For example, posttraumatic stress symptoms related to adverse medical experiences<sup>25</sup> and the family dimensions of cohesion, flexibility, affection, and expressiveness related to improved health outcomes are increasingly recognized as occurring across different physical illnesses.<sup>26-28</sup>

Because pediatric health conditions constitute a heterogeneous group of illnesses with a broad range of severity and functioning, this parameter undertakes a noncategorical approach. However, the approach taken for a given child should incorporate existing knowledge about the specific physical disorder encountered to provide individualized care that is adapted to that child's health condition.

### MODELS OF ADAPTATION AND COPING

The trend in the coping literature has been toward developing integrative models of adaptation to pediatric illnesses.<sup>2</sup> Thompson<sup>29</sup> and Wallander and Varni<sup>30</sup> have developed such models, which display the interconnectedness of child-parent adaptation and adjustment. Thompson uses an ecological-systems theory perspective to develop a transactional model of stress and coping.<sup>29</sup> Chronic illness is seen as a stressor to which the child and family must adapt, and the relationship between illness and adjustment depends on biomedical, developmental, and psychosocial processes.<sup>1</sup> In contrast, Wallander and Varni present a risk and resistance framework of responses to stress, in which children with chronic illnesses display adjustment problems because they are exposed to negative life events.<sup>30</sup> These negative events stem from both their physical illness and associated circumstances as well as from other general life stressors that may or may not be related to the illness. Each of these models has guided a number of research studies.<sup>31,32</sup>

### FACTORS AFFECTING ADAPTATION TO ILLNESS

#### Coping Style

Coping styles—the sets of cognitive, emotional, and behavioral responses to stressors—have been categorized in a number of ways. Approach-oriented coping refers to thoughts or behaviors directed at managing the stressor or feelings it elicits, while avoidance-oriented coping, in contrast, describes efforts by an individual to avoid the stressor.<sup>33</sup> Problem-focused strategies are directed at altering the stressor, while emotion-focused strategies are aimed at regulating emotional responses to the stressor.<sup>34</sup>

The important factor for a child facing an acute medical stressor is not which strategy is used, but rather whether or not the child is allowed to make use of his/her preferred coping style.<sup>7</sup> There is some evidence to support the finding that problem-focused coping may be more adaptive for children with chronic physical illness.<sup>35</sup> The variety, flexibility, and frequency of adaptive coping increase with age, such that older children have access to a wider range of effective coping strategies.<sup>2</sup>

### **Developmental Factors**

Developmental factors have a profound impact on adaptation because they affect coping resources, ability to process and benefit from health-related information, reasoning about illness causality and responsibility, and medical adherence.<sup>2</sup> Preschool children are limited in their ability to comprehend and recall medical information, which can exacerbate emotional reactions to medical interventions.<sup>36,37</sup> While able to better comprehend information, school-aged children may experience loss of control, significant anxiety, and helplessness related to fears about harm to their bodies. Physical illness can impinge on the adolescent's developmental challenges of individuation, and emerging sense of autonomy, bodily integrity, and sexuality, particularly when illnesses involve potential or actual loss of function or alteration of appearance. In contrast to acute illnesses, the age of children with chronic illnesses does not appear to have a significant relationship to behavioral or self-esteem problems.<sup>1</sup>

### **History of Illness and Medical Experience**

Difficult, painful, or unsuccessful medical procedures can fuel future expectations of similar experiences, leading the child to become more anxious.<sup>38</sup> This creates a difficult situation; distress due to negative prior experiences may lead to the avoidance of timely medical care, thereby increasing the likelihood that medical problems will develop that require more intensive and potentially invasive attention.

### **Temperament**

Child temperament can affect adjustment to acute medical stressors directly, or it may moderate their preferences toward particular ways of coping.<sup>39</sup> More anxious children may choose distraction techniques to avoid experiencing an acute stressor, while less anxious children may be more likely to seek information about the stressor. Avoidance may, in turn, manifest itself as treatment nonadherence. There is evidence suggesting that the fit between temperament and environmental influences may be important in determining adjustment.<sup>7</sup> Temperamental difficulties have been found to predict poorer long-term behavioral and emotional adjustment in children with physical illnesses.<sup>1</sup>

### **Parent and Family Factors**

Parental anxiety has been associated with parental distress during procedures, which, in turn, can interfere with parents' abilities to respond to their child's emotional needs, with their abilities to help their child generate effective coping strategies, and with both immediate and long-term outcomes.<sup>7,40</sup> Parental psychopathology, including depression, anxiety, and posttraumatic stress reactions, has been shown to play important roles in long-term child adjustment.<sup>1,9,10,41-44</sup>

Rolland<sup>45</sup> described three family developmental phases (crisis, chronic, and terminal) that are helpful in understanding the impact of physical illness on adaptation. The crisis or acute phase occurs immediately before and after the diagnosis of an illness. Efforts are directed at controlling the illness symptoms and progression while managing reactions to the potential loss of the healthy child. The chronic phase unfolds after the initial diagnosis of and readjustment to the illness. Illnesses can be stable, progressive, and episodic with varying time length so that the goal of this phase is to minimize the risk of relapse through appropriate medical care, while containing the impact of the illness on the child and family. The terminal phase involves managing and processing the feelings and responses to the loss of the child.

## PRINCIPLES

### **Principle 1. *Mental health clinicians should understand how to collaborate effectively with medical professionals to facilitate the health care of physically ill children.***

The mental health clinician working with physically ill children should work toward establishing effective collaborations with primary care physicians and other medical professionals (pediatric health care team). The clinician must demonstrate flexibility and adaptability to perform several roles: evaluation, advocacy, support, and education. See Shaw and DeMaso<sup>7(pp3-6)</sup> for a review.

During the assessment, the clinician's primary role is to identify comorbid psychiatric illness. The assessment should identify direct effects of health conditions that mimic emotional symptoms as well as recognize physical symptoms that are associated with emotional distress. The assessment should identify maladaptive coping styles and behaviors that interfere with a child's health care as well as strengths that promote resiliency. The clinician can advocate with the pediatric health care team on behalf of a child and his/her family through the recognition of the patient's developmental and emotional needs. Finally, the clinician can provide support and education to the pediatric health care team on issues including psychiatric comorbidity, advice on working with families, and countertransference reactions to patients and caregivers.

Collaboration is essential to providing integrated pediatric and psychiatric care, maximizing the pediatric health care team's knowledge and abilities, facilitating an alliance with the family, and contending with constraints within and beyond medical systems. Fritz<sup>46</sup> highlights the value of developing strong relationships between psychiatry and pediatrics as well as the need for joint advocacy efforts. Phillips et al.<sup>47</sup> outline the problems pediatricians face when referring patients for psychiatry services: access to care, quality of service, attitudes of patients and providers, and inadequate communication. They underscore the value of pediatricians maintaining ongoing relationships with mental health clinicians. Shaw et al.<sup>48</sup> describe the current logistical and financial difficulties facing the mental health clinician in providing collaborative care.

It is important for the clinician to communicate his/her findings to medical professionals. In doing so, the clinician should follow the maxim "be available, be understandable, be practical," while taking care to avoid psychological jargon.<sup>49</sup> The clinician should inform the family that his/her findings will be communicated to appropriate members of the pediatric health care team. The family can be told that the clinician and appropriate professional caregivers are required to protect confidentiality under the Health Insurance Portability and Accountability Act (HIPAA). The consultant may also inform the family of situations in which confidentiality cannot be maintained beyond the pediatric setting (e.g., allegations of physical or sexual abuse).<sup>7</sup>

As part of the communication process, a written report should document a summary of the clinician's opinion as well as information necessary for billing and medical/legal purposes. The report should be clear and concise while avoiding personal details that are inappropriate or not required by the medical team, because the medical records may be available to the patient and family for review as well as to outside agencies (e.g., insurance company, social service, court, etc.).<sup>7</sup>

Most children with chronic health conditions are managed primarily by their primary care physician and are not under the care of a pediatric subspecialist.<sup>50</sup> As a result, collaboration will most often be with the primary care pediatrician or family physician. Although all children

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should have a primary care physician, this is not always the case. In these situations, the clinician should work with the family to identify an appropriate physician to assume the child's care. If the child and/or parents are reluctant to seek medical care, the clinician's support and recommendations may be instrumental in accomplishing that important goal. When the child's care involves multiple specialists, the clinician should help the family designate a single physician designated to coordinate the patient's overall care.

### **Principle 2. *The reason for and purpose of the mental health referral should be understood.***

By collaborating with the pediatric health care team and the family to clarify the reasons for and purposes of the referral, the mental health clinician is better positioned to frame an effective intervention.<sup>49</sup> Mental health referrals may be generated from primary care physicians, pediatric specialists, nurses, social workers, child-life specialists, other health care providers, or parents. Before assessing the physically ill child, the clinician should seek answers to the following questions: (1) Who is requesting the referral? (2) What is the reason for the referral? (3) When was the request made? (4) What is the time frame within which to respond? (5) Why is the request being made at this time? (6) Have the reasons for and value of the consultation been discussed with the child and family?<sup>51</sup>

There are typically three overlapping types of responses requested of the clinician by a pediatric health care team: diagnostic (e.g., differential diagnosis of somatoform illness, depression, delirium, or anxiety), management (e.g., procedural distress, disruptive behavior, pain management, nonadherence, parental adjustment to illness, or medication), and disposition (e.g., suicide assessment and psychiatric hospitalization).<sup>49</sup> The relative importance to the medical professionals of each response will vary on a case-to-case basis.

Consultations as part of routine medical management may occur as an integral and preventive component of care for children facing chronic health conditions (e.g., cancer, transplantation) rather than because of a specific emotional or behavioral problem. When psychiatric assessment and management is a routine part of a physically ill child's health care, the patient and family generally feel less stigmatized and more comfortable with mental health involvement.

In the traditional outpatient mental health setting, the family may not understand the reason for the referral and/or may provide an explanation that differs from that of the referring physician. Similarly, in inpatient or outpatient pediatric settings, the family may also be unaware that a mental health referral or consultation has been made. As with any other medical consultation, the treating physician(s) should directly inform the child and family about the referral prior to the assessment. Explanations should include the concerns that prompted the request and the intent of providing comprehensive care to the family. In these situations, the treating physician is the consultee, in contrast to the more typical psychiatric assessment in which the parents are the consulting agents. It is important to consider the family's priorities, clarify the reason for referral, correct any misperceptions, and negotiate appropriate goals. It is important to remember that while a referral may officially come from the child's treating physician, the primary source of the referral may actually be the family, the school, or any of the medical professionals mentioned above.

Formal consent for hospital consultation (whether psychiatric or other medical specialty) is considered part of the authorization for treatment signed by parents at admission to the hospital. If the parent refuses the consultation, the clinician and treating physician(s) should together attempt to define and address the reason(s) for refusal and consider the urgency of the

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consultation. Even in cases where a family refuses the consultation, the clinician can provide valuable advice and support to the pediatric health care team facing a difficult clinical situation.

### **Principle 3. *The assessment should integrate the impact of a child's physical illness into a developmentally informed biopsychosocial formulation.***

The assessment should provide the information necessary for the clinician to generate a developmentally informed biopsychosocial formulation capable of informing management. The components of the "Practice Parameters for the Psychiatric Assessment of Children and Adolescents" are applicable to physically ill children.<sup>52</sup>

### **Obtaining Information From Multiple Sources**

Information should be obtained from treating physicians and other medical professionals. When a child is hospitalized, the medical record should be reviewed and supplemented by information from available pediatric clinicians (e.g., physicians, specialists, nurses, social workers, or child-life specialists). Records of outside mental health and special education evaluations should be reviewed when available. When children are involved with child welfare agencies, the juvenile justice system, and/or are in institutional care, it may be important to obtain records and current information from those sources.

There are occasions in pediatric settings when the treating physician and family may need an urgent psychiatric intervention (e.g., acute panic, disordered mental status, or aggressive behavior). The priority then becomes a focused assessment with corroborating outside information that still must inform diagnosis and initiate a pragmatic management plan that targets the referral concern.

### **Separate Interviews for Child and Parent(s)**

Optimally, patients should be interviewed both alone and with their family. Children are able to listen and ponder information, even while they are very ill. A child's prior experience with medical care may directly influence his/her responses (e.g., a child who has had surgery may be less frightened when seen in an outpatient setting than in the hospital). When approached with sensitivity and respect, children can address their illness or even the possibility of death.<sup>53</sup> Although parents may have difficulty leaving their ill child alone or in someone else's care, it is important to find acceptable substitutes to attend to the child, so parents have an opportunity to speak with the clinician without the child present. Reservation or resistance does not necessarily reflect fear or a lack of understanding, but may be a child's or parent's way of protecting one another.

### **Assessment of Functioning**

Table 2 outlines an assessment protocol for assessing the interrelated domains of illness factors, illness understanding, family functioning, social relationships, academic functioning, coping mechanisms, religion, and relationships with the medical team. See Shaw and DeMaso<sup>7(pp31-58)</sup> for a review. Beginning with open-ended questions in these domains can elicit information that builds alliances and richly informs assessment and treatment. To understand better the relative impact of a physical illness, it is helpful to assess how the child's level of physical functioning compares to that of others with the same illness and/or degree of impairment (e.g., whereas one paraplegic adolescent becomes a wheelchair athlete, another refuses to leave home).

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Physical illnesses and their treatments may impose burdens that significantly affect a child's health-related quality of life.<sup>54</sup> Quality of life is considered to include four domains: disease state and physical symptoms, functional status, psychological functioning, and social functioning.<sup>54,55</sup> While there may be a tendency to dichotomize the assessment into "medical" versus "psychiatric or functional," a child's presentation encompasses an interactive relationship between developmental, medical, emotional, social, and cultural influences, thereby supporting the value of a biopsychosocial approach.

### ***Principle 4. General medical conditions and/or their treatments should be considered in the etiology of a child's psychological and behavioral symptoms.***

Mental health clinicians should be aware that emotional and behavioral symptoms (e.g., anxiety, depression, or aggression) may be direct manifestations of a physical illness and/or its treatment. It is not uncommon for psychiatric symptoms to be attributed to the "stress" associated with a chronic physical illness, particularly when there are other notable psychosocial issues. Generally, each child has both indirect and direct physical illness effects, with the clinician facing the challenge of determining the relative importance of each to the child's current symptomatology.

Clinicians should be knowledgeable about a child's physical illness, including a basic understanding of its pathophysiology, presentation, course, treatment, and prognosis. The clinician should review medical histories, physical examinations, laboratory tests, and diagnostic procedures to confirm that any abnormal results have been addressed. Table 3 lists common laboratory tests and procedures to consider in assessing the presence of a general medical condition.

A comprehensive history of the child's physical condition and its treatment interventions (e.g., medications) is critical to understanding and differentiating indirect (reactive) from direct effects of a physical illness on a patient's presentation. Common manifestations of psychological distress related to the indirect effects of physical illnesses include somatic symptoms (e.g., malaise, pain, irritability, sleep disturbances, and appetite changes), increased attachment behavior (e.g., clinginess), regression (e.g., loss of a developmental milestone), passivity (e.g., helplessness, powerlessness), frightening fantasies about illness or procedures (e.g., ideas of punishment, fear of bodily harm), anxiety, depression, mobilization of defenses (e.g., denial, phobic symptoms, and conversion phenomena) and/or aggravation of premorbid psychiatric symptoms.<sup>51</sup>

The threshold for specific pediatric assessments should be individualized to the child's clinical condition. A clearly defined medical assessment plan helps to assuage parent and child concerns about "missed" illness and avoid aggressive or unnecessary diagnostic testing. The clinician can assist in defining an appropriate limit to invasive tests and procedures and should not hesitate to communicate directly with the treating physician any questions regarding additional and/or continued testing and/or treatment.

### **Delirium**

Delirium is characterized by a disturbance in consciousness, a change in cognition (e.g., memory impairment, disorientation, or language disturbance), or the development of a perceptual disturbance; develops over hours to days; tends to fluctuate during the course of day; and is caused by the direct physiological consequences of a general medical condition.<sup>56</sup> See Shaw and DeMaso<sup>7(pp75-94)</sup> for a review. Manifestations may include aggression, apathy, hallucinations,

inattention, disorientation, language and visuospatial skills deficits, and/or cognitive deterioration.<sup>57</sup> Delirium is associated with rapid and fluctuating mental status changes that require multiple assessments over time to understand the clinical presentation.<sup>49</sup>

Delirium can be a powerful clue to the presence of an unrecognized physical illness and can be a harbinger of serious physical decompensation. Given that virtually any physical condition or medication can be an etiological agent, the clinician must consider multiple etiologies, including infection, withdrawal, metabolic instability, trauma, central nervous system insult, hypoxia, vitamin deficiency, endocrine abnormality, vascular insult, toxins, drugs, and heavy metal pathologies.<sup>58</sup> Of these, the most common pediatric causes of delirium are central nervous system infections (i.e., bacterial meningitis) closely followed by medications (i.e., analgesics and steroids).<sup>59</sup> While the physical cause is being investigated or addressed, the clinician may institute environmental changes and pharmacotherapeutic interventions (e.g., antipsychotic agents) that emphasize safety and orientation.<sup>60,61</sup>

### **Mood and Anxiety Symptoms**

Clinicians should be aware that mood and anxiety symptoms may present secondary to a general medical condition or its treatment. See Shaw and DeMaso<sup>7(pp95-142)</sup> for a review. The depressive symptoms weight loss, appetite changes, sleep problems, fatigue, loss of energy, difficulty thinking, loss of libido, and psychomotor agitation can overlap with numerous physical illnesses including neurological (stroke, postconcussion, epilepsy), endocrine (hypothyroidism, Cushing's syndrome, Addison's disease), and infectious (acquired immunodeficiency syndrome, encephalitis, hepatitis) disorders as well as tumors, failure to thrive, anemia, uremia, and vitamin deficiencies. Analgesics, beta blockers, corticosteroids, immunosuppressants, interferon, oral contraceptives, and chemotherapy agents have been implicated in depressive syndromes. Neurological, endocrine, and cardiac disorders as well as hypoxia, asthma, and diabetes mellitus have been associated with anxiety. Stimulants, anticholinergics, antidepressants, caffeine, steroids, thyroid medications, estrogens, and theophylline have the potential to cause anxiety.

### **Behavioral Difficulties and Somatic Symptoms**

Psychological distress related to the direct effects of a general medical condition can include behavioral difficulties (e.g., aggression) or somatic symptoms (e.g., pain), which can overlap with the indirect effects. Alterations in the child's mental status may reflect medication side effects (e.g., steroids, narcotics, chemotherapeutic agents) or general medical conditions (e.g., anoxia, hypoglycemia). The direct effects of a physical illness may also lead to psychological distress. For example, a child's participation in the assessment may be affected by his/her medical condition (e.g., a child with a cardiomyopathy may be too tired to talk).

### **Principle 5. *Psychopharmacological management should consider a child's physical illness and its treatment.***

The mental health clinician may be called upon to make recommendations about the use of psychotropic medications, including interpreting medication side effects and potential drug interactions. Effective psychopharmacological intervention can help patients relieve emotional and behavioral distress related to their illness or treatment as well as support the medical team in its care of a patient. Although medication use considerations by physicians frequently center on the presence or absence of a psychiatric disorder, medications target specific clinical symptoms

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as opposed to specific diagnostic entities.<sup>7</sup> Common target symptoms and medication considerations are outlined in Table 4.

The clinician should assess the potential influence of psychotropic medications on the child's physical illness and its treatment. There should be a review of current medications, those being considered, and any over-the-counter or complementary preparations. The clinician should consider routes of administration and side effects of recommended medications. The clinician should understand the pharmacokinetic and pharmacodynamic interactions of the medications that are being used or considered.

The clinician will recommend or use medications to treat illnesses that impair different organ systems. It is helpful to follow the maxim "start low, go slow" when initiating medication, particularly in children with hepatic, gastrointestinal, renal, and cardiac diseases, which impact medication pharmacokinetics and pharmacodynamics. In general, psychotropic medication levels are not consistent indicators of either efficacy or toxicity in physically ill patients. If options exist, it is generally preferable to choose a medication with a short half-life and attempt to avoid introducing more than one medication at a time. When possible, medications should be selected that can be administered in a single dose, are easily titrated to an ideal dose, and do not require frequent laboratory monitoring for therapeutic or toxic levels. Multiple medications and demanding treatment regimens threaten adherence.

### Pharmacokinetics

Pharmacokinetics involves the absorption, distribution, metabolism, and elimination of medications.<sup>62</sup> The clinician should consider that medications can be administered by various routes, including oral, intravenous, intramuscular, subcutaneous, rectal, transdermal, and sublingual. With the exception of lithium, methylphenidate, venlafaxine, divalproex sodium, gabapentin, and topiramate, most psychoactive drugs are 80-95% bound to protein. The unbound drug is typically pharmacologically active.<sup>62</sup> The latter point is important because albumin binding is decreased in many illnesses (e.g., liver and renal disease), therefore necessitating adjustments to medication dosages. Medications are primarily metabolized by the liver and gastrointestinal tract and excreted through the kidneys. The clinician should be aware of medications and illnesses that impact hepatic metabolism and blood flow or impair renal excretion. The clinician should be aware of discontinuation effects of psychotropic medications such as the selective serotonin reuptake inhibitor discontinuation syndrome.<sup>63</sup>

The hepatic CYP450 system is responsible for most metabolic drug interactions. Substrates are those medications that are metabolized by specific cytochrome enzymes in this enzyme system. The clinician must be alert to medications that have an inhibitory or inductive effect on a specific enzyme to help avoid potential drug interactions. The uridine glucuronosyltransferase enzymes generally play a minor metabolic role, although lamotrigine, morphine, and lorazepam are primarily metabolized by these enzymes. P-glycoproteins participate in the transport of substances out of the body into the gastrointestinal tract, bile, and urine, tending to function as "gatekeepers" for CYP3A4 metabolism.<sup>62</sup>

### Medication Use in Specific Illnesses

Hepatic Disease: Hepatic disease can impact drug distribution through changes in blood flow, protein binding, and volume of distribution due to peritoneal ascites.<sup>64</sup> As a result, medications may have reduced metabolism and the potential for increased serum drug levels. For example, in contrast to acute hepatitis, where there is generally no need to modify drug dosage,

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metabolism is problematic in chronic hepatitis and cirrhosis, requiring dose alterations. In general, initial dosing should be reduced and titration should proceed more slowly in patients with hepatic disease. Of note, for drugs with significant hepatic metabolism, intravenous administration may avoid first-pass metabolic (CYP450) effects and result in similar dosing and action as in patients with normal hepatic function.

**Gastrointestinal Disease:** Gastrointestinal disease primarily affects drug absorption.<sup>64</sup> Surgical conditions (e.g., bypass surgery) and conditions that divert blood away (e.g., congestive heart failure) may affect absorption. Gastric motility can be affected by medications (metoclopramide, cisapride, and propantheline) and physical conditions (diabetes mellitus and gastritis). Many psychotropic medications, particularly those with anticholinergic side effects, can cause gastrointestinal side effects. Extended-release medication preparations may have fewer gastrointestinal side effects due to more gradual increases in plasma concentrations and are better tolerated in patients with gastrointestinal distress.<sup>64</sup>

**Renal Disease:** Pharmacodynamic effects of renal failure include increased receptor sensitivity.<sup>64</sup> In general, initial doses of medications should be reduced and dosing intervals lengthened in patients with renal failure. The *rule of two-thirds* is that medication doses should be reduced by one-third of the normal dose in patients with renal insufficiency. With the exception of lithium, methylphenidate, venlafaxine, divalproex sodium, gabapentin, and topiramate, most psychotropic medications may not require significant dosing adjustments in patients with renal failure. During hemodialysis, there is an initial lowering of the plasma drug concentrations followed by a rebound after dialysis as the drug redistributes from the periphery to the circulation. Highly protein-bound medications are generally not significantly cleared by dialysis.

**Cardiac Disease:** Congestive heart failure may affect medication by decreasing perfusion of gastrointestinal and intramuscular drug absorption sites.<sup>64</sup> Some psychotropic medications (tricyclic antidepressants, trazodone, thioridazine, and pimozide) may cause orthostatic hypotension, conduction disturbances, or arrhythmias. Quinidine-like effects of the tricyclic antidepressants and antipsychotic agents may lead to QTC interval prolongation and increased risk for ventricular irritability. Stimulants should generally not be used in children with preexisting heart disease (e.g., postoperative tetralogy of Fallot, coronary artery abnormalities, subaortic stenosis, or hypertrophic cardiomyopathy).<sup>65</sup> Patients with risk factors for sudden cardiac death (syncope, palpitations, chest pain, and a positive family history) should be referred for a more thorough cardiac evaluation before beginning treatment.<sup>65,66</sup>

**Pain Complaints:** Pain complaints are affected by the child's ability to communicate, physiological and emotional thresholds, positive or negative reinforcement from parents and professional caregivers, and cultural factors. See Spirito and Kazak<sup>67(pp63-85)</sup> for a review. Infants and young children are at particular risk of being inadequately medicated for pain symptoms. Children may be reluctant to take medication because of the taste, the fear of getting a "shot," the need to be held for its administration, or concerns about medication side effects. When a child in pain is especially anxious or considered to be "manipulative," excessive sedation or suboptimal pain control may result. When using analgesic medications it is important to adopt a preventive approach by treating pain early and aggressively along with medications for anxiety and depression as indicated.<sup>7</sup> The clinician should be aware of potential interactions when combining analgesic medications with other medications, particularly those that could contribute to an increased risk of sedation or respiratory distress. The mental health clinician typically participates in pain management as part of a multidisciplinary team that utilizes both

pharmacological and nonpharmacological modalities (e.g., physical therapy, relaxation, behavioral interventions, family therapy, and psychotherapy). In disabling chronic pain, the clinician can help the family and the pediatric health care team adopt a rehabilitation model, which is focused on adaptation to symptoms that may not resolve.<sup>7</sup>

**Principle 6. *Psychotherapeutic management should consider multiple treatment modalities.***  
**Individual Psychotherapy**

Psychotherapy provides a time and place where patients can effectively voice feelings of fear, anger, and sadness. See Shaw and DeMaso<sup>7(pp263-278)</sup> for a review. Common elements of the interaction include support, reassurance, suggestion, explanation, and introspective exploration of the causes of a patient's feelings of demoralization.<sup>68</sup> The bereavement model has been used to help conceptualize the process of adaptation to a physical illness and to guide treatment intervention.<sup>7</sup> The emotional responses to physical illness or disability can be viewed as a process that begins with shock and denial and proceeds through feelings of anguish and frustration toward an assimilation of illness information and adjustment.<sup>7</sup> Several models of individual psychotherapies are used with physically ill children.

Supportive psychotherapy aims to reduce emotional distress through ego support, enhancement of coping mechanisms, and protection of self-esteem.<sup>69</sup> The goal is to provide education, encouragement, and support by pointing out strengths and correcting misconceptions.<sup>69</sup> Psychodynamic psychotherapy promotes psychological maturation by revealing emotional conflicts that contribute to a child's and family's distress or nonadherence. This therapy is often limited by patients' diminished capacity for self-expression due to the direct effects of their illness, the overwhelming nature of their illness, and the often brief time available for therapy in the pediatric setting.<sup>69</sup>

Narrative therapy or "the story that children tell" regarding their physical illnesses provides opportunities for children and their families to share, organize, process, and validate their experiences. The mental health clinician is afforded entry into both objective and personal attributes of the patient, which facilitates the assessment and subsequent interventions. The child's explanation and beliefs about how and why an illness developed encapsulate the child's deepest convictions and confusions.<sup>70</sup> Studies have shown significant positive effects in patients who have the opportunity to tell their stories or write them.<sup>71-74</sup> Discussion of the physical illness can enhance the mental health clinician's understanding of the child's and family's experiences, facilitate disclosure of psychological material, enrich the therapeutic relationship, and educate the child, family, and clinician. This process allows the clinician to help the child and the family "make meaning" of the adversity, and it can be an important component of resiliency.<sup>75,76</sup>

Cognitive-behavioral therapy (CBT) provides concrete structure to augment the sense of mastery and control, alter maladaptive patterns of thinking, improve problem-solving and social skills, and modify physiological responses.<sup>75</sup> See Spirito and Kazak<sup>67(pp63-85)</sup> for a review. CBT uses behavioral activation, cognitive restructuring, and problem-solving skills to change maladaptive cognitions and coping strategies. It is important to recognize that emotional responses may not be due to cognitive distortion, but rather an appropriate reaction to reality-based distressing life events (e.g., diagnosis of human immunodeficiency virus). Problem-solving and anger control CBT techniques have been used for children facing difficult medical events.

**Behavior Modification**

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Behavior modification interventions target improvements in functional ability and decrease attention to complaints or negative behaviors.<sup>67</sup> Systematic desensitization may be implemented for anxiety symptoms. Behavioral programs with appropriate incentives and an effective system of monitoring and rewards can be tailored for individual patients to reinforce desired behaviors (e.g., medication adherence). Biofeedback, relaxation training, imagery, and hypnosis are based on the premise that decreasing emotional distress and autonomic arousal may improve not only the child's emotional outlook, but also the physical condition (e.g., hypertension, asthma, headache, diabetes mellitus).<sup>77</sup>

### Procedural Preparation and Play Strategies

Children are exposed to multiple invasive medical procedures. Prevention strategies have focused either on identifying risk factors<sup>10,78</sup> or on preparing patients for procedures or hospitalizations.<sup>79</sup> Preparatory interventions generally are designed to provide information relevant to their illnesses or treatment (e.g., preadmission programs, bibliotherapy, or support groups), combined with the modeling of and permission for adverse affective responses (e.g., fear, anger).<sup>79,80</sup> Video games can provide a form of distraction (e.g., facilitating relief from both anticipatory and postchemotherapy nausea) and are appealing because staff participation is unnecessary, costs are low, and the application is easily standardized.<sup>81</sup> Resources from hospitals<sup>82,83</sup> as well as the National Child Traumatic Stress Network's Medical Traumatic Stress Toolkit<sup>84</sup> provide professional caregivers and families with guidelines to recognize symptoms and apply interventions when caring for physically ill children.

Coping strategies during procedures can include breathing, deep muscle relaxation, distraction, behavioral rehearsal, positive reinforcement, modeling, visual imagery, and hypnosis.<sup>67,85</sup> These interventions have consistently been shown to reduce distress and improve cooperation. It is preferable to perform procedures in locations that provide uninterrupted privacy as opposed to settings like inpatient beds. Local anesthesia (e.g., lidocaine-prilocaine cream; Emla<sup>®</sup>) should be used for needle procedures. Parental presence is generally helpful when they are able to assist with nonprocedural talk, humor, distraction, and encouragement.

Play can provide a medium to address reactions related to medical procedures, treatments, or hospitalization. The clinician's tools might include toy replicas or the actual medical equipment (e.g., stethoscope or IV tubing). Sourkes<sup>86</sup> has described the play therapy techniques of letter writing, book illustrating, and therapist monologues. Techniques such as feelings mandala or pie projects, kinetic family drawings, and the Squiggle Game allow the child to express ideas, questions, and emotions as well as to pursue some resolution.<sup>7,87</sup> Whether read between or during therapy sessions, books that include physical illness or medical interventions can stimulate conversations that might not otherwise occur. Computer games involving physical illnesses and their consequences can serve as a discussion forum.

When a child is hospitalized, the common responses of anxiety, fear, anger, and pain are superimposed on the separation from the family and loss of the familiar daily routine. Parents and siblings are similarly affected, although their pain may be emotional rather than physical. However, the comfort of transitional objects (a stuffed animal, an audiotape made by a family member, a favorite CD), parents staying overnight, and sibling visits can mitigate some of a child's distress.

### **Group Therapy**

Group therapy has been found to be beneficial in patients who have shared diagnoses or illness-related issues as well as in patients with various physical illnesses.<sup>88,89</sup> In addition to sharing common experiences, coping strategies, lifestyle changes, and resources, children and families are surprised by how much they offer to others, thereby enhancing their own self-esteem. Support groups provide psychological interventions and input from peers in similar situations through modeling, problem solving, and direct assistance. Psychoeducational groups offer information about the diagnosis, treatments, and psychosocial ramifications of the illness. Adaptation and skills development groups address communication, problem-solving, self-care, and social skills. Symptom reduction groups focus on the decrease or elimination of physical symptoms.<sup>7</sup>

### **Mental Health Clinician Countertransference Issues**

The assessment and treatment of physically ill children and their families evoke significant emotional responses in the mental health clinician.<sup>7,90</sup> These responses may include anger at being “inappropriately” consulted, as well as frustration with the medical staff’s perceived lack of concern or avoidance of difficult parents.<sup>49</sup> Given differences in styles and expectations, the clinician who works with medical caregivers may experience the sense of being a “foreigner, alone among others who do not speak his language.”<sup>46</sup> No clinician is immune to the frustration, anger, sadness, and grief that may accompany physical illness in a child. Such emotions may be related to the illness, child, family, or personal responses intrinsic to the clinician’s own life experiences. When experiencing atypical responses, the clinician should attempt to identify the contributing factors, monitor his/her reactions, and seek support and advice from personal or professional resources.

### **Principle 7. *The family context should be understood and addressed.***

More than 50% of families with a physically ill child establish a healthy level of functioning, although individual family members may be prone to anxiety, depression, anger, and somatic complaints.<sup>91</sup> The degree of predictability, amount of disability, associated stigma, degree of monitoring required, and prognosis are illness factors that impact family adjustment. In addition, parental behavior should be understood in a historical context based on family beliefs and previous experiences with illness and death. Family beliefs are related to commitment, connectedness, and illness permanence. Parental adaptation may be determined by their comfort level when facing situations that range from mastery to loss of control.<sup>7</sup>

At a minimum, parents experience the vulnerability of their child and cope with their inability to protect their child from disease. Successful adaptation requires parents to develop a good understanding of the illness and recognize its potential complications and treatment.<sup>7</sup> Parents may have tremendous fears about survival, a poor outcome, and alteration of lifestyle, which may be manifested as anxiety, guilt, depression, or anger.<sup>49</sup> Because of their own inability to cure their child and the necessary reliance on professional help, parents are obliged to surrender certain degrees of control and may need to forsake their traditional roles. They can become preoccupied with medical details, while psychosocial factors are ignored, considered a lower priority, or deemed irrelevant. Family responses may vary from being focused on obtaining data, to entrusting caregivers without reservations, to entitlement.<sup>49</sup> Often, one family

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member manifests a style that is counterbalanced by that of another (e.g., one parent is preoccupied with technical details while the other manifests more affect).

The burdens and stress of having an ill child affect the parental relationship.<sup>92</sup> Although many parents are able to support each other and become closer, the risk of displacing anger onto one another is high, especially if conflict existed prior to the illness. When there are genetic contributions to the illness or a caregiver has been responsible in some way for the illness, self-blame or accusations directed at the significant other are common. These reactions are often part of a parent's defense mechanism against his/her own grief about the child.

Studies have documented both beneficial and deleterious effects of parents' affect and behavior on the physically ill child.<sup>7</sup> Supportive responses are preferable, including a calm parental presence.<sup>93</sup> However, parental anxiety, criticism of the child's emotional reactions or behaviors, threats, punishment, or excessive parental attention to a child's distress (e.g., reassurance, empathy, apologies, relinquishing control to the child) can exacerbate a child's distress and compromise coping abilities.<sup>94,95</sup> The continuation of familiar "family rules" and appropriate limit-setting are helpful in signaling children that they are safe. On the other hand, overprotectiveness has been shown to have negative consequences.

Because a child's illness can have prolonged effects on parents and siblings, the mental health clinician should consider a follow-up screening or assessment for depression, anxiety, and posttraumatic stress symptoms several weeks or months after an initial evaluation.<sup>42,43,96</sup>

### Siblings

In general, siblings of chronically ill children show a greater likelihood of behavioral difficulties and increased shyness or anxiety when compared with control subjects.<sup>67,97</sup> Siblings are faced with the challenge of competing with a physical illness, which may be depleting other family members' limited emotional and financial resources.

Depending on illness severity, siblings may be unable to engage in activities with the affected child, solicited by parents to make sacrifices, and confronted with distressing responses or questions from peers. They often experience physical abandonment or a sense of emotional disengagement by their parents, who are with or emotionally preoccupied by the ill child. Siblings may be jealous of the attention the ill child is receiving. Parents may become angry and unrealistically expect the siblings to comprehend medical issues beyond their developmental capacity. Identification with the ill child may occur, especially if the ill child and sibling have the same or a similar health condition (e.g., cystic fibrosis, asthma), in which case comparison and competition are bound to develop. Siblings may be confused about the illness and may have magical thoughts that their own feelings somehow caused the condition. Well siblings may experience guilt about not being affected.

If a sibling's achievements surpass those of the child who has the physical illness, the roles and self-images of both children may be altered. Siblings may inherit responsibilities for the ill child and assume a parental role for the ill child or other siblings. They may also experience a loss of opportunities, because they must be home after school to help with tasks rather than participate in after-school activities, or cannot participate in educational or social opportunities because of the family's compromised finances. This can occur on an occasional or long-term basis, depending on the availability of the parents and the degree of physical disability in the patient.

### Family Therapy

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Family therapy can shift the focus away from the physically ill child as the identified patient, allowing each family member to “tell the story” of his/her own experiences in a safe and professionally guided arena.<sup>7</sup> See Spirito and Kazak<sup>67(pp36-60)</sup> for a review. Even children who are too ill or cognitively limited to participate in individual psychotherapy may benefit from the family sessions. Ideally, the clinician should feel comfortable meeting with family members in various permutations (e.g., the family as a unit, siblings or parents with or without the ill child, each individual alone).

As legal guardians, parents are responsible for making decisions and ensuring their child’s care. Parents’ emotional health and functioning exert a formidable impact on children’s emotional well-being, affect medical care and adherence, and influence interactions with professional caregivers. It is incumbent upon the clinician to form an alliance with parents and involve them actively. Because parents’ sense of competence is easily threatened by medical problems, they may assume that sophisticated approaches are beyond their capabilities. The clinician can help define which areas require further education, but in most circumstances he/she can remind parents of the experiences, strategies, and skills they already possess. In addition to acquiring formal education about the child’s medical needs, caregivers can benefit from learning strategies to help cope with the psychosocial ramifications of the illness (e.g., administering an insulin injection in a nonpunitive way that minimizes parental guilt).

Age-appropriate education for parents about their child’s illness sets the stage for the child to assume increased responsibility for his or her care (e.g., to perform urinary self-catheterization). Parents often know their children best and can make excellent judgments about such milestones. However, some parents may feel uncomfortable about or unwilling to cede their responsibilities, perhaps because of inadequate understanding or their own emotional needs.

### **Principle 8. *Adherence to the medical treatment regimen should be evaluated and optimized.***

Failure to follow through with treatment regimens is a major health concern.<sup>98,99</sup> Reviews suggest that 33% of patients with acute health conditions and 50-55% of those with chronic illnesses fail to adhere to their treatment regimens.<sup>99,100</sup> Nonadherence may result in poor medical outcome, increased financial costs, and decreased quality of life. Individual, family, disease, and treatment correlates have been identified as important risk factors for treatment nonadherence (see Table 5). Studies on the efficacy of treatment interventions responding to these correlates have been limited by small sample sizes, inability to generalize findings, and difficulties standardizing adherence measurement.<sup>100</sup> Based on the major etiological factors related to adherence, current treatment approaches involve educational, organizational, behavioral, and psychotherapeutic interventions (see Table 6). Spirito and Kazak<sup>67</sup> have outlined specific family therapy techniques including normalizing adolescent rebellion, improving family communication, and implementing family problem-solving strategies as means to promote adherence.

### **Principle 9. *The use of complementary and alternative medicine should be explored.***

Complementary and alternative medicine (CAM) comprises a group of diverse health care practices that are used either together with conventional medicine (complementary) or instead of conventional medicine (alternative).<sup>101</sup> Families or clinicians may consider CAM when conventional treatments are deemed unacceptable or insufficient. Treatments such as acupuncture, herbal remedies, homeopathy, massage, and spiritual healing have been used for centuries, but they have not been subjected to the rigorous trials on which modern practitioners

rely. Data on the safety and effectiveness of these approaches are particularly limited in children. CAM treatments may harbor unrecognized dangers as a consequence of the physical illness itself or interactions with medication. Moreover, dependence on these treatments may exclude the use of curative interventions. Although often underreported by patients and parents to health care providers, the practice of CAM appears to be increasingly prevalent in children, particularly among those with chronic illnesses.<sup>102-104</sup> Therefore, it is important for the clinician to explore with the family their use of CAM treatments. The clinician should be open to discussion with patients and families of the risks, benefits, and gaps in knowledge pertaining to these treatments, recognizing their motivation to seek all potentially effective interventions. Patients and families should be helped to feel comfortable discussing CAM with their pediatric health care team.

**Principle 10. *Religious and cultural influences should be understood and considered.***

Cultural and religious beliefs may affect the child's and family's understanding of medical issues, acceptance of intervention, treatment adherence, and ultimately prognosis.<sup>105</sup> There is growing evidence that racial and ethnic minorities are at greater risk for morbidity and mortality with a number of chronic illnesses, particularly those associated with social and behavioral factors.<sup>106</sup> Recognition of the family's beliefs and traditions may identify potential sources of support for the child and facilitate the working relationship between the family and professional caregivers.

When differences of opinion arise, the mental health clinician should help assess the medical and psychological risks and benefits of the proposed intervention or withholding (e.g., when a Jehovah's Witness family refuses a life-saving transfusion). It is incumbent on the clinician to recognize that such convictions may hold profound meaning to the family, rather than being a manifestation of "resistance." Clinicians should consider others' perspectives and wishes, educate themselves about a family's beliefs, be aware of their own countertransference, and always be respectful.

Language barriers may contribute to confusion, misunderstanding, isolation, suboptimal care, and errors in diagnosis or treatment. Although some families may feel uncomfortable with a stranger serving as an interpreter, it is preferable to avoid the temptation of allowing the child or a family member to translate. Ideally, the interpreter should have experience working in the medical care setting. When an on-site interpreter is not available, speakerphones or telephonic interpretation services can be utilized. Hospitals and outpatient medical facilities are required to provide interpreter services to meet the needs of a culturally diverse patient population.<sup>107</sup>

**Principle 11. *Family contact with community-based agencies should be considered and facilitated where indicated.***

**School**

Physical illness may interfere with the child's academic and social functioning as well as engender anxiety in peers and teachers.<sup>108-110</sup> The mental health clinician can help improve collaboration between health care and school systems.<sup>92</sup> School interventions can include educating school personnel and peers about the physical illness and its treatment, advocating for special services, participating in academic decisions (e.g., having a child attend summer school or repeat a grade), or identifying activities the child can participate in despite time or physical limitations (e.g., being an assistant coach or working backstage in a theater production).

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The federal special education law, the Individuals with Disabilities Education Act, in combination with a state's special education law(s), guarantees students with disabilities in public schools an Individualized Education Program (IEP) designed to meet their unique needs. These laws ensure that a physically ill child can attend school with necessary supports (e.g., transportation, accessibility, aides, computers, and communication devices). The IEP documents specific needs relevant to the physical illness, and it may be revised if warranted by changes in the child's functioning. When the child's level of physical disability (e.g., heart failure) prohibits school participation, homebound instruction should be instituted (illness permitting). If school absence appears to be primarily for emotional reasons, a plan should be developed to return the child to school. The clinician can help parents to secure appropriate and necessary services for the child.

### **Social Service Agencies**

Social service agencies have resources relevant to responding to the day-to-day needs of parents with physically ill children (e.g., home health supports, respite care, transportation, day care for healthy siblings, or financial resource advice). Access to these services and resources can be voluntarily sought out by parents with support and direction from the clinician or the pediatric health care team.

Parents may become overwhelmed by the treatment regimen. This commonly occurs in individuals who are struggling with additional psychosocial stressors (e.g., emotional, physical, social, or economic difficulties). The clinician must be alert to medical neglect. Although child protection agencies are ultimately responsible for decisions regarding neglect or abuse, the clinician may be asked to help assess a parent's ability to care for the child. The clinician can provide a psychiatric assessment to the pediatric health care team that includes information about parental psychopathology and the parent-child relationship. The clinician should avoid assuming a detective role in identifying the perpetrator and victim. In such circumstances, the clinician should explicitly inform the child and parents that the findings are not confidential or privileged and must be communicated to the team.

Physically ill children may require a "medical" foster home because of the complexity of the child's care or the parents' limited abilities. A child who has major physical needs or a terminal disease may require foster parents who are specially trained and willing to assume the additional burdens of the child's care and prognosis.

### **Community Resources**

The clinician should be knowledgeable about community-based resources that can help reduce the pragmatic and emotional burdens of dealing with a pediatric illness. Hospitals and other community programs may have parent support groups that are devoted to specific illnesses. Clergy and members of religious congregations are of invaluable support to some families. They can also provide education to the medical team about the family's religious beliefs. Specialized day treatment facilities (e.g., for medically ill infants or children with brain injuries) can reduce the daily burdens of home care, offer education to families, and provide contact with other children and families in similar situations. Camps for children with specific physical illnesses (e.g., diabetes mellitus, heart disease) offer safe care, education, and opportunities for more independence and peer interactions for the child, while providing parents a much valued respite. Parents themselves become expert advocates who, in turn, become resources to other families.

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A myriad of national organizations provide education and support for specific physical conditions (e.g., asthma, cystic fibrosis, inflammatory bowel disease, spinal cord injury) or are devoted to children with physical illness (e.g., Make a Wish Foundation). Family Voices and The Federation for Children with Special Health Care Needs are two agencies that provide services and information to families who have children with special health care needs and help them to network with other families. These groups often have important information about eligibility for services and are powerful advocates for the needs of children in their communities. Both condition-specific and general organizations offer educational literature, conferences, contacts with other families, local resources, and occasionally financial aid.<sup>70,111-113</sup> Together with the family, the clinician can identify those organizations that can provide additional support.

Given the often inordinate cost of physical illness, even when insurance is available, the clinician should encourage parents to explore their eligibility for state or federal financial and management benefits. Community fundraising can offer additional financial resources and a gratifying validation of others' caring. When presented with the poignant case of an ill child, community business organizations may provide equipment or services (e.g., computer hardware or software, lumber or labor costs for a wheelchair ramp). Some groups provide free air travel to patients who live at a distance from medical treatment. Local or national newspapers, television, or radio may advocate on behalf of an individual child or family as well as for others with similar physical conditions.

### ***Principle 12. Legal issues specific to physically ill children should be understood and considered.***

The mental health clinician should have a working understanding of the legal and forensic issues related to treatment consent, confidentiality, and privilege. The clinician should be aware of relevant statutes in his/her jurisdiction and should know when to obtain legal consultation. See Shaw and DeMaso<sup>7(pp59-74)</sup> for a review.

Consent and authorization are required for all medical treatments and procedures except in unusual circumstances. Informed consent requires that patients or legal guardians (if the patient is a minor) receive from their health care providers a full and reasonable explanation of the risks and benefits of treatment, including no treatment, and possible alternative treatments.<sup>114</sup> This issue is more complicated with children, because minors are generally considered to be incompetent to make medical treatment decisions, and parents or legal guardians provide the consent. There is increasing recognition that most adolescents have the capacity to participate in decision making and a greater willingness by parents and the medical team to include them in the decision making.<sup>114</sup> Assent (an agreement to participate) is a method of involving minors in treatment decisions. The clinician can serve an invaluable role in helping the pediatric health care team and family navigate the developmental issues involved in the medical decision-making process.<sup>7</sup> Important exceptions to the rule requiring parental consent prior to treatment include emergency treatment, emancipated minors, mature minor exception, reproductive health, alcohol and substance abuse treatment, and mental health treatment.<sup>7</sup>

It may be necessary to seek legal recourse from a child protective agency or the court when refusal of treatment endangers the child's life or health or when more than one individual (e.g., parents with joint custody; a parent and mature minor) has legal rights to make decisions but disagree (e.g., ventilatory support or use of controversial medication). It may be necessary to obtain medical guardianship when a patient who has attained the legal age of majority is not competent to make his/her own decisions (e.g., brain injury, mental retardation). In addition to

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the medical risk or benefit, the psychological ramifications to the child of a specific treatment need to be considered (e.g., transplantation, religious beliefs that forbid blood transfusions). Ideally, a formal assessment is performed by individuals who have expertise in medical decision-making and, if possible, experience with the specific condition (e.g., a psychiatrist who is a member of the transplantation team or consultant to the intensive care unit). An ethics committee may offer additional guidance. The clinician needs to be aware of relevant statutes in his/her state.

The clinician must be alert to issues of confidentiality and privilege. The clinician is legally and ethically mandated to protect the confidentiality of information in his/her clinical work. Privilege governs the disclosure of information in legal and administrative proceedings. These issues can be complicated in physically ill children whose parents are entitled to access information to help make treatment decisions or to enhance continuity of care.

### ***Principle 13. The influence of the health care system on the care of a physically ill child should be considered.***

The mental health clinician's appreciation of the ramifications of physical illness should include recognition of the complex practical and financial burdens that affect the child's and family's emotional state, behaviors, lifestyle, illness treatment, and, ultimately, health outcome. Families are often confronted with limitations in obtaining necessary or optimal care. Many medical expenses are not covered by insurance (e.g., specialized infant formulas, supplies, uncompensated time away from work, parking for medical appointments). It is often difficult to find a clinician who is knowledgeable about and experienced in physical illnesses, and even when identified, the preferred clinician may not be contracted with the family's insurance company.

Children with both acute psychiatric needs and complex or life-threatening physical conditions who require care that cannot be managed responsibly in an intensive psychiatry treatment setting can be hospitalized on a medical unit. Because such an environment does not thoroughly address the patients' psychiatric needs, some hospitals create units with both psychiatric and medical resources. When facilities are far from the family's home, the health care providers may be forced to choose between optimal care for the child and the inconvenience and stress of frequent travel. The clinician, pediatric health care team, and family share the responsibility of securing a safe environment for the child and advocating so that financial concerns do not compromise care.

Despite their best intentions, primary care physicians and pediatric specialists are increasingly limited in their ability to devote the necessary time to counseling families, may not have a long-term relationship with the child and family, and are adversely affected by financial considerations (e.g., capitation, reimbursement by diagnosis rather than time spent). Mental health consultation during a hospital admission generally requires an extensive time commitment that is reimbursed suboptimally. Outpatient medical and surgical interventions are facing increasingly less time and reimbursement for multidisciplinary consultations regarding children with complex, co-occurring emotional and physical illnesses.

Nevertheless, attention to mental health issues in children with physical illnesses has the potential to improve their medical outcome, as well as to potentially decrease short- and long-term financial costs (e.g., medical caregiver appointments, evaluations, hospitalizations, loss of work income). Primary care physicians are striving to increase the identification and early intervention of psychiatric problems in their practices. Inpatient and outpatient pediatric facilities

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are developing collaborative relationships among medical, psychiatric, and family support services to assist patients and families in need of additional emotional support. As individuals or as part of a local or national organization, clinicians should act proactively to educate and effect appropriate changes (e.g., advocating that a hospital be financially responsible for the consultation-liaison service, consulting to third-party payers, and presenting evidence of needs to a state or the federal legislature). In addition to the potential for decreasing direct and indirect financial burdens to patients, families, and society, timely mental health intervention serves to maximize the quality of life of physically ill children and their families.

### PARAMETER LIMITATIONS

AACAP practice parameters are developed to assist clinicians in psychiatric decision-making. These parameters are not intended to define the standard of care; nor should they be deemed inclusive of all proper methods of care or exclusive of other methods of care directed at obtaining the desired results. The ultimate judgment regarding the care of a particular patient must be made by the clinician in light of all the circumstances presented by the patient and his/her family, the diagnostic and treatment options available, and available resources.

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**TABLE 1. COMORBIDITY OF PSYCHIATRIC SYNDROMES RELATED TO PHYSICAL ILLNESS**

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**Psychiatric syndromes related to physical illness**

- Coincidental comorbidity
    - Emotional disorders related to factors other than physical illness
  - Causal comorbidity
    - Psychosomatic disorders
      - Physical change secondary to psychiatric symptoms
        - Malnutrition secondary to eating disorder
        - Transplant rejection due to nonadherence
      - Somatoform disorders
        - Pain disorder
        - Conversion disorder
    - Somatopsychic disorders
      - Psychiatric symptoms secondary to general medical condition
        - Delirium secondary to medication
        - Mental disorders due to a general medical condition
      - Psychiatric symptoms as a reaction to illness/treatment
        - Adjustment reaction
        - Posttraumatic stress disorder
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Source: Shaw and DeMaso, 2006, Chapter 1, pp 8.

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**TABLE 2. PROTOCOL FOR THE PSYCHIATRIC ASSESSMENT OF THE PHYSICALLY ILL CHILD**

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- **What are the illness factors?**
    - Stage – new, relapse, chronic
    - Course – relapsing, single event, interinterval recovery, chronic deteriorating
    - Prognosis – preservation of function with treatment, decline, terminal
    - Treatment – hospitalizations, clinic visits, medications, adherence, traumatic procedures
  - **What is the understanding of the illness by the child and parent?**
    - How explained, realistic comprehension, adequate understanding, cognitive factors, cultural issues
  - **What is the emotional impact of the illness on the child?**
    - Premorbid, current, degree of acceptance
  - **What is the impact of the illness on family functioning?**
    - Family, marital, occupational, financial issues
  - **What is the impact of the illness on the healthy siblings?**
    - Decreased parental availability and/or resources, emotional reactions
  - **What is the impact of the illness on social and peer relationships?**
    - Stigma, decrease contact, impact on dating and sexuality
  - **What is the impact of the illness on academic functioning?**
    - Premorbid, current, problems with school reintegration, special education needs
  - **What are the child's habitual coping mechanisms?**
    - Family, friends, religious, social withdrawal, denial, avoidance, maladaptive coping
  - **What is the role of religion and spirituality?**
    - Affiliation, beliefs, role as social support in family
  - **What is the relationship of the family with the medical team?**
    - Level of trust, quality of communication, family's involvement in decision making
- 

Source: Adapted from Shaw and DeMaso, 2006, Chapter 3, pp 43-45.

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**TABLE 3. LABORATORY TESTS AND PROCEDURES IN THE ACUTE ASSESSMENT OF A GENERAL MEDICAL CONDITION**

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**Basic laboratory tests**

- Complete blood cell count, electrolytes, glucose, blood urea nitrogen, creatinine, total protein, liver function tests, calcium, magnesium, phosphorus, thyroid function tests, pregnancy test, and urinalysis.

**Additional laboratory tests**

- Arterial blood gases, heavy metals screening, serum B<sub>12</sub>, folate, lupus erythematosus prep, antinuclear antibody, urinary porphyrins, ammonia levels, erythrocyte sedimentation rate, and human immunodeficiency virus.

**Medication-drug screen**

- Serum drug levels (lithium, anticonvulsants, tricyclic antidepressants, digoxin, and cyclosporine) and urine toxicology screen.

**Procedures**

- Chest x-ray, lumbar puncture, computed tomography scan, magnetic resonance imaging, electroencephalogram, electrocardiogram, echocardiogram, and endoscopy.

**TABLE 4. TARGET SYMPTOM APPROACH IN PEDIATRIC CONSULTATION**

<b>Target symptom</b>	<b>Medication considerations</b>
Agitation	Atypical or typical antipsychotic agent Benzodiazepine
Anxiety	Diphenhydramine (younger children) Benzodiazepine Antidepressant Buspirone Gabapentin Clonidine
Delirium	Atypical or typical antipsychotic agent
Depression	Selective serotonin reuptake inhibitors Norepinephrine selective reuptake inhibitors Stimulant
Fatigue	Stimulant Selective serotonin reuptake inhibitors Modafinil
Inattention	Stimulant Atomoxetine Bupropion
Insomnia	Diphenhydramine Benzodiazepine Trazodone Hypnotics (e.g., zolpidem or zaleplon) Mirtazapine
Pain	Tricyclic antidepressants Norepinephrine selective reuptake inhibitors Analgesic Anticonvulsants
Psychosis	Atypical or typical antipsychotic agent Benzodiazepine
Withdrawal	Benzodiazepine Clonidine

Source: Shaw and DeMaso 2006, Chapter 15, pp 306.

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**TABLE 5. RISK FACTORS ASSOCIATED WITH PEDIATRIC TREATMENT NONADHERENCE**

<b>Correlates</b>	<b>Risk Factors</b>
Individual	Past history of poor adherence Adolescence History of behavioral difficulties Past emotional difficulties Presence of denial regarding illness Low self-esteem Internal locus of control
Family	Lack of parental supervision Parental conflict Parental psychopathology Poor family support Low socioeconomic status Lack of family cohesion Poor pattern of family communication
Disease	Long duration of illness Illnesses with few symptoms Feelings of pessimism regarding illness
Treatment	Complexity of the treatment regimen Unpleasant medication side effects Low level of perceived efficacy of treatment Treatment with high financial costs

Source: Shaw and DeMaso 2006, Chapter 11, pp 230.  
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**TABLE 6. TREATMENT ALGORITHM FOR PEDIATRIC TREATMENT ADHERENCE**

PRIMARY REASON FOR NONADHERENCE	TREATMENT MODALITY
Forgetfulness	Increased parental supervision. Memory aids (e.g., pill boxes, pagers, telephone reminders).
Inadequate awareness of consequences of nonadherence	Re-education of patient and family regarding medical issues.
Lack of appropriate parental supervision of treatment: <ul style="list-style-type: none"> <li>• Lack of awareness of need for parental supervision.</li> <li>• Logistical issues (e.g., working parents).</li> </ul>	Education of the family regarding adolescent developmental need for supervision. Establishment of effective system for supervision of treatment.
Adolescent developmental issues: <ul style="list-style-type: none"> <li>• Cognitive immaturity.</li> <li>• Acting out of separation conflicts.</li> <li>• Adolescent omnipotence/denial.</li> <li>• Peer group issues.</li> </ul>	Education of the family. Increased parental supervision. Behavioral interventions (i.e., incentives, behavior modification programs). Possible referral for individual and/or family therapy in refractory cases.
Family psychopathology: <ul style="list-style-type: none"> <li>• Parental conflict.</li> <li>• Parental disorganization.</li> <li>• Poor communication.</li> <li>• Parental psychiatric illness (e.g., depression, substance abuse).</li> </ul>	Family therapy. Possible referral of parent for individual psychiatric treatment.
Psychiatric illness: <ul style="list-style-type: none"> <li>• Depression.</li> <li>• ADHD.</li> <li>• Posttraumatic stress symptoms.</li> <li>• Oppositional defiant disorder.</li> </ul>	Individual psychotherapy. Family therapy. Possible use of psychiatric medications.

Source: Shaw and DeMaso, 2006, Chapter 11, pp235-236.

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