

Treating Parents of Children With Chronic Health Conditions: The Role of the General Psychiatrist

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Abstract: Pediatric chronic health conditions are quite common, affecting one-quarter of children and adolescents in the U.S. As a result, general psychiatrists will regularly treat adult patients whose children have chronic conditions. These conditions may be physical, mental, or developmental but all have a major impact on the lives of parents/caretakers and families. Taking a biopsychosocial approach to understanding the types of problems these parents and families face, this article delineates the domains of challenges posed by children with chronic conditions along with practical strategies for the general psychiatrist treating the adult parent/caretaker. Systemic thinking and acting “family” opens up possible interventions and can lead to improved outcomes for the general psychiatrist’s patient as well as their children.

INTRODUCTION

Definitions for pediatric chronic health conditions vary from a simple listing of specific conditions to consideration of impairments, functional limitations, and service utilization (1). For the framework of this review, chronic health conditions are defined, similar to Stein and colleagues (2), as any health condition that lasts or is expected to last more than 12 months (dating from time of diagnosis) AND that causes at least one of the following: impairments, functional limitations, and/or the need for medical or care services. Common childhood chronic conditions include but are not limited to: asthma, allergies, diabetes, obesity, psychiatric and developmental disabilities, especially autism spectrum disorders, intellectual disability (formerly referred to as mental retardation) and ADHD. The category also includes less common conditions, such as cystic fibrosis (CF), leukemia, congenital heart conditions and sickle cell disease. The number of children and adolescents in the United States with a chronic health condition has increased over the last four decades (3). According to Halfon and Newacheck (4) the incidence increased from 1.8% in the 1960s to more than 25% in 2007. Similarly, Van Cleave and colleagues (5) found the rate of chronic

illness doubled in the last two decades to approximately 26% using data from the Longitudinal Survey of Youth. This rise is a result of improved survival rates for multiple childhood conditions such as cystic fibrosis and leukemia; increased rates of common childhood conditions such as obesity, asthma, and ADHD; and improved survival of low birth weight infants and infants with severe birth defects. In addition to improved survival and treatments, changes in societal expectations and funding have led to greater numbers of children with chronic conditions living with their families, placing greater strain on parents and siblings (6). While large numbers of children have chronic conditions, much fewer have impairments or functional limitations. An estimated 3% of all children have a chronic condition that causes impairment or functional limitations (7).

Author Information and CME Disclosure

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Drs. Smith and Kaye report no competing interests.

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While substantial numbers of these children have traditional medical conditions, the largest percentages have developmental or psychiatric conditions (3).

An individual's health can affect the entire family, in turn, impacting individual health outcomes; thus providing a comprehensive therapeutic approach to childhood chronic conditions requires a focus on the whole child and their family (8). Childhood chronic conditions involve all family members and impact the daily function of the family through the direct effects of the illness and its treatments, as well as through emotional and behavioral responses to the illness. The illness may place a burden on family finances and change the economic status of the family, impact social interactions, and increase the vulnerability for psychological and psychiatric disturbances. These burdens are an additional risk for family dysfunction and negative health outcomes not only for the child but also the parents and caregivers. Because of the widespread prevalence of childhood chronic conditions, the general psychiatrist needs to be aware of the impact on their adult patients of having a child with such a condition. This review focuses on the impact on the family with an emphasis on clinical implications for the psychiatrist working with adult patients. The impact of life threatening situations, while a critical aspect of some conditions, is assumed but is beyond the scope of this article. Before considering the ways in which having a child with a chronic condition impacts parents, we begin with an overview of the psychological experience of parents and caregivers to provide an important context for appreciating the domains of parent or caretaker's life that are affected by pediatric chronic conditions.

THE PSYCHOLOGICAL EXPERIENCE OF PARENTS AND CAREGIVERS

Given the long term nature of chronic conditions there can be many similarities to a long term grieving process, with each life cycle stage bringing another wave of emotional reactions. The range of parental reactions to a child's chronic illness varies from adapting well to experiencing severe stress associated with guilt, shame, blame, anger, or reduced self-esteem. While parents often respond with resiliency and signs of positive mental health, many also struggle with their emotional reactions. Parents of children with chronic health conditions face two basic issues (9): the first is learning to deal with their child's health, and the second is coping with the stress. Chronically ill children and their parents may experience guilt at the existence of this chronic illness. Children may experience guilt around the

burden their illness places on the family. In the case of a genetic medical condition or with a medical setback, parents may experience guilt as they question whether they have done enough. Another source of guilt can be unacceptable feelings of anger due to a parent's sense of burden, unfairness, or frustration with the child. Not uncommonly parents feel shame over having a child with a chronic condition (particularly psychiatric or neurodevelopmental) that may be stigmatized by extended family, the community, or media. Blaming themselves or their partners for "causing" a psychiatric condition through imperfect parenting is also common.

Parental avoidance, denial, and guilt can lead to conflict between a parent and child. The avoidance may cause a child to feel isolated if they are unable to talk about their illness experience or feelings of guilt. Denial can have a negative impact on treatment and a psychiatric consult may be considered. Attempts to "make up for" the child's condition can interfere with optimal growth and development. It can be quite a challenge to determine what a child can and cannot do, and coming to terms with the existential issues can be painful for all.

Everyday parenting of a chronically ill child can be a challenge. Normative misbehaviors in preschool years can complicate management of many chronic illnesses. For example, in a study of young children with type 1 diabetes, parent stress was related to ratings of problematic child behavior which tended to be developmentally normal but frequently directly relevant to the diabetes management (10). Many parents find it very difficult to discipline their chronically ill child, yet all children need clear limits and consistent expectations. Parents may also lower their expectations of a child with an illness. Parents may need help in establishing a consistent set of expectations and managing behavioral difficulties which may need to be adjusted as the child's health fluctuates. When a child with a serious or life threatening illness becomes a teen, parents need to navigate less supervision and greater independence. As stakes can be higher for the child's wellbeing, parental anxiety can fuel the intensity of normal separation-individuation struggles of children as they grow up. Conflict can arise out of well intentioned supportive behaviors that become counterproductive, such as overprotective parenting. This conflict has been shown to be associated with negative health outcomes for children, predicting lower adherence for teens with CF (11) and poor metabolic control for teens with diabetes mellitus (12).

With this psychological understanding of the parents' experience, the paper will now delineate the biopsychosocial domains that are impacted by

pediatric chronic conditions (see Table 1), along with considerations of how these issues manifest themselves in the lives of parents and the other caretakers. These sections will be followed by a discussion of the special considerations in children with chronic psychiatric or neurodevelopmental disorders. Finally, the paper concludes with practical suggestions for addressing the needs of the adult psychiatric patient within these clinical contexts.

FAMILY FUNCTIONING AND STRESS

While childhood chronic illnesses vary in etiology, clinical characteristics, and treatment regimens, children with a chronic illness and their families share a number of challenges in common. Including the medical and mental health histories of children during a routine general psychiatric assessment is crucial, as living with a child with a chronic illness has profound effects on the entire family, especially

parents. Taking care of a child with an ongoing health problem can be one of the most difficult tasks a parent faces. Parents need to assist their child in coping with the demands of their illness while they manage both everyday and illness related caretaking responsibilities. Challenges can include: complex or daily medical treatments that may continue for years, strain on time, financial burdens, and impairments in a parent's ability to work outside the home. A challenge that bears particular attention is sleep disruption for others (e.g. parents) in the family and this will be addressed in a separate section below. In addition, siblings may need to defer their needs as the child with a chronic illness becomes the focus of attention. All of these challenges can have repercussions on the physical and emotional well-being of each family member as well as on the quality of the relationships within the family.

While many parents are able to adjust to their child's illness through various coping mechanisms

Table 1. Biopsychosocial Framework for Childhood Chronic Illness: Impact and Intervention

Biopsychosocial Domain	Impact	Consequences	Strategies
Family Functioning	<ol style="list-style-type: none"> 1. Marital satisfaction 2. Sibling effects 3. Extended family 	<ol style="list-style-type: none"> 1. Marital stress and divorce 2. Sibs can feel "less important" or receive less attention, leading to greater family stress or mental health issues in sibs. 3. May add stress to grandparents or others, which in turn adds stress for parents 	<ol style="list-style-type: none"> 1. Psychoeducation about potential family impact 2. May need to make adjustments in career development at times 3. Community or hospital based parent/family support groups (often have sibling components) 4. Family therapy 5. Short breaks for parents, family
Parental Mental and Physical Health	<ol style="list-style-type: none"> 1. Mood disorder 2. Anxiety 3. PTSD 4. Psychosis 5. Substance abuse 	Increased risk of psychiatric episode, leading to "vicious cycle" of child impacted further, which further impacts parent/caretaker, and so on	<ol style="list-style-type: none"> 1. Psychoeducation for adults who are parents of children with chronic illness 2. Increase support and appointments during times of increased stress 3. Review prodromal symptoms to be on look out for 4. Prompt treatment of increased signs of new episode 5. Use of parent support groups 6. Short break/ respite services
Parental Sleep	<ol style="list-style-type: none"> 1. Physical state 1. Mood 2. Cognition 	<ol style="list-style-type: none"> 1. Elevated BP 2. Impaired immune function 3. Increased risk of obesity 4. Precipitate mood episode 5. Impaired concentration, memory 6. Increased risk of MVA 	<ol style="list-style-type: none"> 1. Psychoeducation about effects of sleep deprivation 2. Encourage naps 3. Short break ("respite") services 4. Maintain healthy nutrition, exercise 5. At least yearly PCP appointment 6. Encourage own psychological and psychiatric treatment
Family Economic/ Financial Health	<ol style="list-style-type: none"> 1. Employment 2. Noncovered expenses 	<ol style="list-style-type: none"> 1. Missed work, negative impact on work performance 2. Financial stress and bankruptcy 	<ol style="list-style-type: none"> 1. Be aware of provisions of family medical leave act and employer policies for work absence, sick leave. 2. At times may need medical excuse to care for child 3. Referral for financial guidance

and supports, one study found nearly half of parents of children with different chronic illnesses were at risk for impaired quality of life (13). The challenge for parents is to balance the demands of caring for a chronically ill child with maintaining their physical and emotional health and their quality of life. These experiences may place a strain on a parent's coping and the increased stress of having a child with a chronic condition has been associated with exhaustion and parental burnout. Increased rates of parental burnout, experienced as emotional fatigue, physical weakness and cognitive symptoms, occur more often in parents of children with chronic diseases than parents of healthy children and are among the long term consequences of parenting a child with a chronic illness (14).

Medical regimens can change a family's routines and priorities, making the management of typical family tasks more challenging. Chronic or recurrent hospitalizations, frequent medical appointments, and complex physical care all can require much parental time. Psychiatrists treating parents should be informed on the child's condition and the treatment demands (resources include UpToDate, Medscape eMedicine, The American Academy of Pediatrics). In some cases demands can restrict a family's social or leisure activities or limit a parent's occupational/professional career. Parents often find it difficult to go out alone without their children because babysitters or day care cannot be easily accessed or because the parents are concerned with untrained caregivers following the child's medical regimen. As the illness becomes more time-consuming there may be limited attention and time for other family members, most notably for siblings, contributing to sibling rivalry and attention seeking behaviors by healthy siblings (15–17). Siblings may also experience higher rates of distress and psychopathology (18–21). Social relationships, outside the immediate family, may also become strained during medical illness as everyone adjusts to the situation and their new responsibilities. Additionally, the child's condition may also strain a marriage. While the type of support needed from family and friends may vary depending on the illness trajectory, research indicates that support itself is crucially important for both emotional and physical functioning (22). Maximizing opportunities for children and parents to experience positive relationships both in the home and outside the immediate family may buffer some of the negative effects of having a child with a chronic illness. Additionally, psychiatrists treating parents may find it helpful to provide a referral to a support group or for family-based assessment and intervention (see Table 1, Strategies column).

PARENTAL MENTAL AND PHYSICAL HEALTH

Parents' mental and physical health are commonly impacted by their children's chronic condition. Parents of chronically ill children are at elevated risk for psychiatric disorders (23), which in turn places their children at an increased risk for poorer health outcomes (24). The parent's mental health typically fluctuates over time, and is influenced in part by their personal experience of their child's illness. Parental mental health issues can impact parent-child bonding and child development. This is perhaps even more salient when a child is chronically ill and there are long term implications for the parent and child.

Parents appear to be most at risk for internalizing symptoms and disorders, including depression, anxiety, and stress syndromes, particularly post traumatic stress disorder. Parents predisposed to psychosis or substance use disorders can be assumed to be at elevated risk of precipitating episodes at times of high stress although this has not been specifically reported on in the literature regarding children with chronic conditions. For assessment of potential substance use disorders consider screening questionnaires such as the CAGE (http://www.merfweb.org/files/resources/cage_info_scoring.pdf) or the CAGE-AID (<http://www.agencymeddirectors.wa.gov/Files/cageover.pdf>) if illicit drug use is suspected, with follow up diagnostic interviews for those with positive screens. For a current review on assessment and treatment of substance use see Tinsley (25). Additionally, the University of Washington maintains a useful database of substance use assessment instruments at <http://lib.adai.washington.edu/instruments/>

Numerous studies across chronic illnesses have found increased rates of depressive and anxious symptoms in parents and caregivers. In 2007, The Cystic Fibrosis Foundation funded The International Depression/Anxiety Epidemiological Study (TIDES) to assess the international prevalence rates of mood disorders in patients with CF and their parents. Preliminary TIDES findings in the United States using data on 492 mothers and 131 fathers indicated that among mothers of children with cystic fibrosis 51% had elevated anxiety scores and 26% had elevated depression scores, and in fathers 44% had elevated anxiety scores and 20% had elevated depression scores (26). Similarly, mothers of young children with diabetes report elevated symptoms of anxiety and depression, with as many as 20%–25% exceeding clinical cut-offs (27). Another study found that as depressive and anxious symptoms increase, parental quality of life declines (28). In addition, parental depressive symptoms have been

linked to lower child medication adherence (29, 30) and thus poor health outcomes. As more literature emerges on the need to screen parents of chronically ill children in the pediatric setting parents identified with depressive and anxious symptoms will be referred to adult psychiatrists for treatment. Effective treatment of depression offers the promise of improvements in the psychological functioning and well-being of the parent, thereby enhancing completion of daily tasks, improving treatment adherence and optimizing appropriate health care for the child.

Recently post traumatic stress disorder (PTSD) has been a lens through which a child or parent's experience with chronic illness, particularly a life threatening condition, can be understood. Frightening aspects of the illness or its treatment may be re-experienced, nightmares may occur, and parents may experience withdrawal and isolation. A meta-analysis on the prevalence of PTSD in parents of children with chronic illness found one out of four parents of children with a chronic disease fulfilled the criteria for PTSD and the prevalence was higher in mothers than fathers (31). The presence of PTSD symptoms may compromise care-giving abilities and have a significant impact on adherence and treatment. Periodic assessment for traumatic medical events may be warranted with screening of parents with a recent traumatic event, a new diagnosis of a potentially fatal disease, or after a child is admitted to an intensive care unit or has invasive procedures. The American Psychiatric Association Practice Guideline for the Treatment of Patients With Acute Stress Disorder and Posttraumatic Stress Disorder (32) recommends monitoring for posttraumatic symptoms along with a validated self-rating measure, such as the PTSD Checklist, the Impact of Events Scale (available online at www.mardihorowitz.com) or the Davidson Trauma Scale to assess the full range, frequency, and severity of posttraumatic symptoms and the related distress and impairment.

In addition to mental health problems, parents of children with chronic health conditions have also reported poorer physical health. In a large population based Canadian study, caregivers of children with complex health problems were more likely to have their own health problems than did caregivers of healthy children (33). Given these health risks and that safe and effective mental and physical health care requires collaboration and communication it is important to develop a working relationship with the parents' primary physician.

PARENTAL SLEEP

Children with chronic conditions often have sleep disruptions. Consequently parents of children with

chronic illness also often experience sleep disruptions. Parents may be required to be medical caregivers at night, aroused by an awakened child, or preoccupied with worries of the child's illness. Sleep disturbances of parents include insomnia, poor sleep quality and frequent night time awakenings. A recent review (34) concluded that parents of chronically ill children have elevated rates of sleep disruption and that these disruptions may mediate the increased rates of stress, depression, anxiety, and fatigue reported in these parents. Further consequences of disrupted parental sleep may include poorer daytime functioning, including greater daytime sleepiness, lowered frustration tolerance, impaired attention and memory. Last, it is well known that sleep disruption can precipitate and promote the continuation of mood disorders, an additional concern for predisposed parents of chronically ill children (35). Have a high index of suspicion for insomnia or sleep difficulties if a parent complains of or evidences fatigue or excessive daytime sleepiness, complaints of poor memory or difficulty concentrating, or has worsening of their depressive or anxious symptoms. The diagnosis of insomnia is typically made clinically and is dependent on the following criteria: the complaint of difficulty in initiating sleep and/or maintaining sleep or nonrestorative sleep that results in daytime impairment.

FAMILY ECONOMIC AND FINANCIAL HEALTH

Child chronic health conditions can cause a substantial financial hardship and overall negative economic impact on the family. A national U.S. study reported that 40% of families of children with special health care needs experience a financial burden due to their child's condition (36). Families from lower socioeconomic backgrounds and those lacking adequate health coverage are particularly vulnerable. The condition may impair a parent's work attendance or their ability to continue to work thereby jeopardizing insurance coverage. A 2005-2006 National Survey of Children with Special Care Needs indicated that 24% of parents reported stopping or cutting back on work because of the child's condition (37). In addition, out of pocket expenses for medical treatments and procedures can be enormous and may obligate parents to change jobs or seek additional employment. Finally, for some families the distance from services may require the family to relocate closer to the medical services a child requires. Consideration of such barriers in the treatment of parents with mental illnesses may help improve adherence.

SPECIAL CONSIDERATIONS IN CHILDREN WITH CHRONIC NEURODEVELOPMENTAL OR PSYCHIATRIC CONDITIONS

AUTISM AND DEVELOPMENTAL DISABILITIES

The latest figures put the prevalence of autism spectrum disorders (ASD) at over 1% of the pediatric population (38). ASDs are highly heritable and as a result many parents will share characteristics of their affected child. While parents impact the child, the child just as certainly impacts the parent/caretaker. This dynamic transactional model makes it difficult to separate out cause and effect. Nevertheless, it is clear that parents of children with ASD experience greater stress, lower levels of physical and mental well being, and higher levels of depression than parents of typically developing children (39–42) as well as children with other chronic health or developmental conditions (43, 44). It has been proposed that a significant factor in the greater stress for parents of children with ASD is the much higher frequency of behavior problems, especially externalizing problems (43–47). Children with autism also generally have significant problems initiating and maintaining sleep, often to a severe degree in younger children (48). Because of the high needs of these children, parents spend much extra time providing care for them. It is estimated that on average this amounts to 6 hours per day (49), 3–4 hours above that required by a typically developing child (50). This not only impinges on work outside the home, but also on other family and leisure time. Siblings often need to set their needs aside, although they may also benefit from the added responsibilities and opportunity to care for someone else. The literature suggests that siblings may be at heightened risk for negative well being (17). While marital stress is well documented (51) it has also been often asserted that parents of ASD children have high rates of divorce. While one case control study supports this (52), a large, population-based study does not (53) and suggests that rates of divorce are no different from the general population. Social support moderates the impact of having a child with ASD for parents (40). Last, expenditures for health care are greater for families of children with ASD (54, 55) and are associated with an average of \$6200 income loss or 14% of total income (56) adding to the family experience of stress.

While parents of children with other developmental disabilities (DD) (e.g. intellectual disability or mental retardation, cerebral palsy, Fragile X, Down Syndrome, etc.) experience many of the same difficulties as those whose children have ASD

the degree of impact appears to be less. Levels of distress and depression (40, 57, 58), time demands (50), physical (59) and economic stress (56, 60) appear to be elevated compared with typically developing children but lower than parents of children with ASD. This may be partially explained by the lower level of psychiatric genetic risk for parents of children with developmental disabilities, as compared with parents of children with ASD. Another factor in the relatively lower stress levels may be the lower frequency of behavior problems seen in the broad DD population as compared with children with autism (60–64). When behavior problems are seen, rates of distress are equal to those of parents with a child with autism.

ATTENTION DEFICIT HYPERACTIVITY DISORDER

ADHD is one of the most common childhood psychiatric conditions, affecting roughly 7% of children (66). Like autism, ADHD is a highly heritable condition, so cause and effect are difficult to sort out in any discussion of the relationship between childhood ADHD and the family. Direct and indirect bidirectional effects lead to complex gene-environment interactions that impact both child and caretakers/parents. While undoubtedly parents have a major impact on the development of children with ADHD (67), these children's effects on parents are also considerable. An estimated 25%–50% of children with ADHD have sleep difficulties (68, 69). From early on it has been recognized that parents of children with ADHD, especially younger children, report elevated rates of stress (67). A major confound in the literature is the high rate of comorbidity with other externalizing disorders (Oppositional defiant disorder or ODD and Conduct disorder or CD) that, as noted above in the discussion about autism, are major contributors to family stress in their own right. It appears that rates of distress are high in parents of children with ADHD alone, but are highest in families of children with ADHD complicated by another externalizing disorder (67). The impact of child ADHD on the marriage of the parents has been investigated in a number of earlier studies (70–72) which reveal lower marital satisfaction and greater conflict than control parents. Rates of divorce in parents of young children with ADHD are 2–3 times higher than controls (70, 72). Rates of psychiatric disorders including depression, anxiety, ADHD, substance abuse, and antisocial problems are higher in parents of children with ADHD (67). Shared genetic vulnerabilities with parents and the impact of the child's behavior on the parents contribute further to high rates of psychiatric disorder in the parents. ADHD itself is

associated with parental depression, although the genetic links appear strongest in comorbid ADHD/CD (67). The impact of the child's behaviors on the parents has generally been thought of as a moderating variable on parental psychiatric disorder rather than a primary etiologic factor. Last, economic analyses have documented the substantial burden childhood ADHD has on parents and families with higher health care costs and more days of work lost (73–75).

OTHER PSYCHIATRIC DISORDERS

While it can be assumed that having a child with other significant psychiatric disorders (e.g. Bipolar disorder, psychosis, Schizophrenia, substance abuse) is associated with major challenges for parents there is little literature on the impact of these specific disorders on parents and caretakers. The literature on the impact of adult onset schizophrenia and psychosis on caregivers is beyond the scope of this article. For a thoughtful, recent review of the literature on caretaking in adult onset schizophrenia see Awad and Voruganti (76) and the 2009 PORT Guidelines (77).

PRACTICAL RECOMMENDATIONS FOR TREATING PARENTS/CAREGIVERS WITH A CHILD WITH A CHRONIC CONDITION

By appreciating the widespread impact of chronic illness on families, general psychiatrists can be enormously helpful to their adult patients who have children with chronic conditions (61, 78, 79). In addition to improving child outcomes, interventions addressing key issues can directly improve their patient's lives. Multiple domains of the adult's life may be negatively impacted by a child's chronic condition and require specific interventions. All this translates into elevated risk for the general psychiatrist's adult patients. Strategies to address each affected domain are described in Table 1 (Strategies column) and summarized in Table 2. All adult patients need psychoeducation regarding their own condition, including an appreciation of the symp-

toms, especially those heralding increased difficulty, the risk and protective factors, and treatments for their condition. This becomes especially important in the context of having a child with a chronic condition, as these children's difficulties pose added risks for the adult psychiatric patient. The parent's psychiatrist can be instrumental in providing support and education for parents to appreciate their need for sufficient sleep and encouragement to "take care of themselves" while caring for their child. Recommendations may include encouraging naps or taking turns being responsible at night with another adult. The same goes for adequate exercise and nutrition which are crucial for the parent's mental and physical health, which in turn are critical for optimizing the child's health outcomes. Psychiatrists can also be instrumental in assisting their adult patient's understanding of the family stressors involved, including sensitizing them to the increased time demands, sense of increased stress, strain on marriages and siblings posed by children with chronic conditions. At the same time, psychiatrists can help their patients recognize that a chronically ill child can pose opportunities for developing strengths in the individuals (adults and siblings) as well as the family as a whole. Psychiatrists should encourage and support short breaks (80), which may involve informal (e.g. babysitters, family, friends, neighbors) or formal ("respite" care) arrangements. It is essential for both parents, as well as siblings with their parents, to have time away from a chronically ill child. General psychiatrists may also be able to provide much needed family therapy to address issues raised by a chronically ill child. Support groups (e.g. Epilepsy Association, CHADD, Cystic Fibrosis Foundation, NAMI, etc) can be crucial to parents as well (81), providing education, practical solutions, as well as psychological and social support (for a list of disease specific resources see www.cdh.org/Medical-Services/Pediatrics/Parenting-resources/Disease-Specific-Resources.aspx). Other community based support groups in the natural environment (e.g. church, temples) can also provide support for parents. Last, psychiatrists should be aware of the financial stressors associated with children with

Table 2. An Integrated Clinical Family Perspective for General Psychiatrists

1. Provide psychoeducation about impact of chronic condition on family and parents, and how this might influence adult psychiatric conditions as well as family relations (including siblings)
2. Be aware and utilize family support groups (e.g. CHADD, CF Foundation, Epilepsy Association, etc)
3. Be aware of availability of short break ("respite") services
4. Recognize adult patient's prodromal symptoms along with prompt adjustments in treatment
5. Emphasize need to address regular sleep, exercise, nutrition needs
6. Consider need for family therapy
7. Provide work support for parents if needed, including understanding Family Medical Leave Act and provisions for parents

chronic conditions and be familiar with the Family Medical Leave Act (www.dol.gov/whd/fmla and <http://www.wrightslaw.com/advoc/articles/fmla.protect.spolter.htm>) and its provisions for parents. At times a medical leave from work for parents is necessary. These are typically recommended by the child's treating physician or team but psychiatrists need to be aware of the implications for their adult patients and be prepared to advocate for their needs.

CASE EXAMPLES

I have been seeing my patient, a 37-year-old mother, for 1 year for medication management and weekly psychotherapy for depression. She is preoccupied with her struggles with behavioral issues in her 8-year-old son who had a benign brain tumor removed 9 months ago. He has symptoms of what sound like separation anxiety and attentional problems. Parenting is a major stressor for my patient. It is easy for sessions to be devoted to parenting strategies. I also wonder whether some of the discussion of the child may be defensive, i.e., a way to avoid dealing with some of her own issues. I don't want to dismiss her concerns regarding the child, but also don't want to enable her avoidance. Many of our sessions feel centered on the child. How should I approach this with my patient?

First, recognize that children with chronic conditions often stimulate powerful emotions in psychiatrists as well as parents. There is little on earth that stimulates more affect than a sick child, let alone one with a potentially life threatening condition. Depending on the condition, the range of feelings in the psychiatrist toward the parent can run from compassion to pity and aversion, to sadness, and to anger and guilt. Frustration with parents is not unusual, especially if one hears about pathogenic interactions with children that further complicate a medical or neuropsychiatric condition. It is not clear in this case what your patient's part in the interaction with the child has been, and while I would not assume that there are major parenting issues, I would be vigilant for signs of the impact of the mom's depression on the child and family. Providing an empathic context for the patient who is certainly shouldering more than her fair share of cosmic burden, as always, is crucial. At the same time thinking "family" (i.e. understanding what impact your patient has on her partner and children and vice versa) allows you to understand your patient more deeply and broadly. This also may open up alternative intervention strategies.

Staying within a context of individual supportive or insight-oriented psychotherapy, there are times that sensible behavior management suggestions may be very helpful. If it becomes clear that the parent is

having difficulty carrying out the behavioral suggestions then the focus can be shifted to what is interfering with the mother's acting productively. This is in line with what family therapists have taught for years by shifting focus from the symptomatic child to the interactions and relationships. Another approach to the patient's focus on her child to the exclusion of herself may be to ask how the child's behaviors are impacting her life. That is, given how difficult the child's problems are and the feelings stimulated, how does she take care of herself? Is she sleeping adequately? Does she get sufficient exercise to support her physical and emotional health? Does she feel the siblings are reacting to a loss of attention? How is this affecting the marital relationship? Looking for clues and exploring what is interfering with her caring for herself emotionally can be fruitful. Finally, a third approach would be to start with the parent's focus on the child's behaviors and explore the fears and meanings that the behavior has for her. For example, is the child's separation anxiety triggering mom's fears that the child may have a life threatening condition? Does the mom have a history that has sensitized her to separation issues? The trick is how to accept the patient where he/she is, focus on the child, and then gently shift the focus to your patient's part in the interaction. From there it is a short leap to a focus on her inner experience of herself and her relationships with other important people.

Alternatively, thinking "family" you might consider bringing the mom's partner and/or child in for one or more conjoint interviews with the mom. This would bring out a great deal of information useful in the treatment of the mom. It is always instructive, and sometimes quite surprising, to actually meet the family members that adult patients speak so frequently about. In addition you may be able to intervene more productively and efficiently in relation to the mom's difficulties with her son as well as her symptoms.

I have a patient who is a 44-year-old single mother who I am treating for depression and anxiety. She has a 6-year-old son with autism and presents with a sea of questions about her son's diagnosis, behavior, and treatment. He is aggressive, acting bizarrely (cut off his braces), and has been physically striking out at her. He is frequently up at night and the mother is concerned about what he might do while awake, resulting in her sleep being disrupted. She missed her last appointment with me because she had to pick her child up early from school after the Principal called stating the child's behavior had been out of control. The child's primary medical doctor has recommended treatment with risperidone. She inquires "how abnormal is this behavior" and is seeking advice on the appropriateness of risperidone. How should I answer her?

Listen, clarify the parental concern, and encourage her to talk with the child's primary care provider (PCP). Because parents of these children often feel a sense of blame and/or shame, reassurance that autism is a neurobiological disorder and that they are not to blame for the child's condition can be crucial. Further, recognition that these children can be very challenging and that behavior problems are not unusual can be quite relieving. However, you should typically not advise about a specific medication decision without a thorough understanding of relevant information about the child. Understand what is behind your patient's question and explore the concerns implicit in her question, "how abnormal is this behavior?" Empowering your patient to assert herself with the PCP to obtain answers to her questions would be ideal. When the child's condition, treatment, or prognosis cannot be clarified by the parent, direct contact with the PCP and members of the child mental health and school team can be helpful to you in treating your patient. This is especially true in situations in which the parent has significant psychiatric (e.g. schizophrenia, psychosis, drug abuse) or cognitive (brain injury, borderline intellectual functioning) conditions that make it difficult to advocate for themselves or their child. In these situations it can be especially important to involve other family members (e.g. partners, parents, other supports) in treatment. This may not only assist your patient in distributing the stress of caring for the child but also ensure that the child is being adequately cared for. At times, adult psychiatrists may be in a position where, in their role as a mandated reporter, they need to involve Child Protective Services. Examples include the adult patient with substance abuse who reports driving their child while intoxicated, or the actively psychotic or manic adult patient who is neglecting their child or putting them in harm's way. Conversely, it may be helpful for you to provide information that helps the PCP understand mom better, promote a treatment alliance, foster adherence to the child's medical treatment regimen, and coordinate efforts if needed.

Missed appointments can be complex situations for parents with a child with a chronic condition. Often there are reality based issues that do interfere with meeting other life responsibilities and it may be very difficult to tease out whether there are concomitant issues of avoidance at play. In this situation the patient, a single mother, has missed only one appointment and behavioral problems in children with autism that prompt school disruptions are not uncommon. In general, especially at the beginning of a treatment it is better to err on the side of empathically recognizing and accepting the difficulty

the parent had in attending a session. Listening for signs of whether this reflects undue stress is important and may lead to problem solving with the patient about the support she has and identifying resources that do or can help her with meeting her caretaking responsibilities. When a patient misses multiple times or has a defensiveness about the missed session(s), it can be useful to take a "yes and" approach, acknowledging the difficulties posed by the child but also asking whether they are aware of any feelings (about therapy, the therapist, the child, someone else) that might be interfering with their attending. At times it can be important to help the patient recognize that removing a child from an activity may serve as a counterproductive shielding of the child from participating in developmentally appropriate activities (e.g. school, extracurricular activities, peer activities). Assisting parents in distinguishing a normal protective stance with a sick child from shielding the child from responsibility or normative activity is essential.

Support services in the community are crucial for a mother in this situation. The importance of informal social support from friends, family, and naturalistic institutions (church, synagogue, mosque) cannot be overstated. Bringing in close friends, parents, or others who may be able to provide support to one or more sessions should be considered. Formal support services in the community can also be useful. For example, an autism parent support group or short breaks (formal or informal "respite") can be lifesaving. The adult psychiatrist can provide key assistance if aware of the need for these services and how to access them. Although adult psychiatrists are unlikely to be familiar with the specific groups available, guidance about how to identify these services (for example, many communities have a clearinghouse for child services like Parent Network) can be invaluable. A local child psychiatrist colleague should be a good resource for you as well in identifying services.

In both of these cases, there is an ongoing question of how much the parent's therapist should be involved with the child's treatment and clinicians. In general, it is a good idea to obtain consent to have discussions with the child's teachers and/or clinicians as needed. While not often needed, there may be times, when your appreciation of the child and family's needs (often best known by the other clinicians) helps you assess the level of competence of and stress experienced by your patient. This is often helpful as you get another view of her requirements, and her abilities to cope and implement care for her kids and family. Your knowledge of her capabilities may also help the child's team appreciate their need for additional or other services to compensate for any deficiencies in the parent. Occasionally

you might consider family and/or team meetings with the patient's consent, if you feel this is an important part of her treatment. This does not imply that you will provide parent guidance for child issues if you are not qualified or experienced in doing so. On the other hand, your input into the care of the child and how the child's needs impact your patient, enhances your understanding of stresses on the mother, and your ability to provide support.

CONCLUSION

Chronic illness affects a broad range of areas in children and families, including social relationships, and personal, emotional, and physical well-being. Psychiatrists need to assess the burden and strain on the parents and families of children with chronic illness with attention to family factors, such as parenting style, family functioning, and child and parent psychopathology. Supporting families, and in particular parents, is crucial for both child and parent mental and physical health. General psychiatrists can play a key role in providing such support to parents and caretakers of children with chronic conditions.

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