HOSPITAL-TO-SCHOOL TRANSITION FOR CHILDREN WITH CHRONIC ILLNESS: MEETING THE NEW CHALLENGES OF AN EVOLVING HEALTH CARE SYSTEM

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Chronic illness is common and has a profound impact on the education of affected children. A variety of approaches and programs to facilitate the transition from hospital to school for children with chronic health problems has been described in the literature. Traditional transition plans may no longer be effective because medical service delivery has changed to reduce long-term hospital stays while increasing outpatient care. As a result, comprehensive hospital-to-school transitions increasingly emphasize home and family involvement that includes homebound instruction strategies, flexible school days, using differentiated instructional strategies, increasing child autonomy, and addressing affective issues. This article describes the needs of children with chronic illness, identifies educational programming consistent with the current health care system, and describes current hospital-to-school transition plans that integrate systemic needs of schools and health care systems with the needs of children with chronic illness. © 2007 Wiley Periodicals, Inc.

Current estimates indicate that 18% of all children have a chronic illness, and 6.5% suffer an illness severe enough to interfere with normal school activities (American Academy of Pediatrics, Council on Children with Disabilities, 2005). Approximately 1.5% of children are unable to regularly attend school due to chronic illness (Kaffenberger, 2006). The challenge to professionals is developing and implementing hospital-to-school transition plans that accommodate students with a diversity of medical conditions in an environment of changing medical and educational systems. The development and implementation of effective hospital-to-school transition plans can ameliorate the functional effects of chronic illness (American Academy of Pediatrics, Committee on School Health, 1993). Foremost among the goals of a hospital-to-school transition plan is the need to improve school attendance among children with chronic illness.

Chronic illness is a medical condition of extended duration that creates impairment in adaptive behavior and socially defined roles. Adaptive behavior includes communication, daily living, self-care, academic functioning, and motor behaviors (Notoras et al., 2002). Socially defined roles include play, social interaction, family roles, and schooling (Prevatt, Heffer, & Lowe, 2000). Fifteen to 20% of North American children have ongoing health care needs due to chronic illness (Newacheck et al., 1998). Although chronic illness encompasses heterogeneous medical issues, a common feature of chronic illness in children is the degree to which they have difficulty with school attendance and performance due to symptoms and unintended effects of treatment.

CHRONIC ILLNESS AND SCHOOLING

Children with chronic illness are absent from schools for an average of 16 days a year compared to around 3 days absent for healthy children (McDougall et al., 2004). However, some chronic conditions take a more profound toll on school attendance. For example, children being treated for childhood leukemia miss an average of 40 school days during the first stages of treatment and have inconsistent attendance for the 3 years that follow (Prevatt et al., 2000). In Table 1, some examples of chronic childhood illnesses, as well as corresponding treatment regimes, side effects, and average

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<table>
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<tr>
<th>Illness</th>
<th>Treatment</th>
<th>Side Effects of Illness and/or Treatment</th>
<th>Average Range of School Absence&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Reference(s)</th>
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<tbody>
<tr>
<td>Asthma</td>
<td>Inhalant medication therapy (beta-agonists, corticosteroids); leukotriene modifiers; antihistamines</td>
<td>Malaise; drowsiness and fatigue; sleep loss; hypoxia; temporary fine-motor dysfunction after using beta-agonists</td>
<td>12 – 36 days</td>
<td>Bender (1999)</td>
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<tr>
<td>Cancer</td>
<td>Chemotherapy; radiation therapy; surgery; bone marrow transplants; medication</td>
<td>Nausea and gastrointestinal problems; fatigue; hair loss; pain; anemia; increased infections; skin irritation; loss of appetite</td>
<td>Dependent on nature of cancer and treatment; average from 25 to 80 days</td>
<td>Vance &amp; Eiser (2001)</td>
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<tr>
<td>Cystic fibrosis</td>
<td>Nutrition monitoring, including high calorie diet; growth hormone; pancreatic enzymes; drugs for respiratory symptoms; chest physiotherapy</td>
<td>Stunted height and weight growth; pulmonary difficulties associated with excess mucosa; decreased appetite; fatigue; body image problems related to stunted growth</td>
<td>Wildhagen et al. study: 19.5 days</td>
<td>Strawacker &amp; Wellendorf (2004); Wildhagen et al. (1996)</td>
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<td>HIV infection</td>
<td>Antiretroviral medications (often used in combination therapy with at least three drugs)</td>
<td>Increased risk of infections due to immunosuppression; adverse drug effects (e.g., lactic acidosis, hepatic toxicity, pancreatitis, metabolic abnormalities such as abnormal fat distribution or hyperglycemia, bone marrow suppression, allergic reactions)</td>
<td>Cohen et al. study: 10 – 40 days; 3% were too ill to attend school, and another 5% were home schooled</td>
<td>Cohen et al. (1997); Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children (2006a, 2006b)</td>
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<tr>
<td>Insulin-dependent diabetes mellitus</td>
<td>Insulin monitoring and injections; dietary management; exercise</td>
<td>Acute hypo- or hyperglycemia (ketoacidosis), affecting attention, memory, learning, and processing speed</td>
<td>14 days</td>
<td>Desrocher &amp; Rove (2004); Holmes et al. (1999)</td>
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<tr>
<td>Traumatic brain injury</td>
<td>Hospitalization and treatment of open or closed head injury; pain management; cognitive, behavioral, and socioemotional interventions</td>
<td>Broad range of deficits, including speech and motor functioning, memory, sensory processing, cognition, and socioemotional functioning</td>
<td>Mean length of hospitalization: 46 days; additional school absence may be required for rehabilitation</td>
<td>Clark et al. (1999)</td>
</tr>
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<sup>a</sup>Mean school absences for healthy children are approximately 3 – to 3.5 school days a year (McDougall et al., 2004).
numbers of school absence, are provided. There are a number of factors that influence school attendance, with the child’s specific diagnosis not always being the best predictor (Madan-Swain, Katz, & LaGory, 2004). Rather, the chronicity of the illness, parental response to the illness, parental educational level, and ability of the child to participate in physical activities are better indicators (Cook, Schaller, & Krischer, 1985; Sexton & Madan-Swain, 1993). Model school reentry programs target school attendance as a primary goal to reintegrate the child into the academic programming and to symbolize a return to normalcy (Kaffenberger, 2006).

CHRONIC ILLNESS AND SYSTEMIC ISSUES

Life expectancy and functional abilities of children with chronic illness have increased greatly (Falvo, 2005). Children with cancer, HIV/AIDS, cystic fibrosis, and other severe chronic illnesses are living longer and have more functional skills due to advances in medical treatment (Weller, Minkowitz, & Anderson, 2003). Despite the impressive advances in medical care, children with chronic illness are at increased risk for academic and psychosocial difficulties (Armstrong, Blumberg, & Toledano, 1999). With more children with chronic illness surviving, there is an increased burden on schools to support effective transition and provide educational and psychosocial programs (Shapiro & Manz, 2004).

Many children with chronic illness are eligible for special education services under the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) or educational accommodations under Section 504 of the Rehabilitation Act of 1973 in the United States, and under provincial laws creating equal opportunity consistent with the Charter of Rights and Freedoms (1982) in Canada. The “Other Health Impaired” category of IDEIA provides individualized educational programming for children who have long-term medical conditions that result in impairments of academic or social functioning (IDEIA, 2004). Section 504 is a civil rights law requiring that schools make accommodation to ensure that all students have equal access to educational opportunities. The charter is interpreted by each province in Canada and shares many components of IDEIA and Section 504.

There is much information describing the shortcomings of the U.S. and Canadian health care systems (Canadian Institute for Health Information, 2005; Gladwell, 2005). The United States has significant issues with uninsured and underinsured populations, increasing out-of-pocket expenses, and concerns about which procedures are covered by insurance companies (Newacheck, Park, Brindis, Biehl, & Irwin, 2004), whereas Canada has serious problems with access to physicians, rural health care, and variations in the provincial control of health care (Eisenberg, 2006). However, both nations share the drive to cut the costs of health care. For pediatric populations, the most common method of holding costs down is to reduce the frequency and duration of inpatient care (Sturm & Bao, 2000). Hospital stays of longer than 1 week are relatively rare for children (Wazeka, Valacer, Cooper, Caplan, & DiMaio, 2001). However, children with serious injuries such as burns or head trauma, children with severe infections, and children at an end stage of their illness tend to have long hospital stays (Landrigan, Conway, Edwards, & Srivastava, 2006). Children with chronic illness, including life-threatening illnesses such as cancer, rarely involve extended hospital stays (Newacheck et al., 2004; Wazeka et al., 2001). For example, one study reports that the current average hospital stay of children admitted with an asthmatic crisis is less than 2 days, whereas only 5 years ago such a hospital stay averaged 4 days (Landrigan et al., 2006). Although financial considerations drive the movement toward increased outpatient care and treatment, the increased effectiveness of medical treatments is another important factor. Outpatient care is now the norm for children with chronic medical issues in both the United States and Canada (Landrigan et al., 2006; Newacheck et al., 2004).
PREVIOUS MODELS OF HOSPITAL TO SCHOOL TRANSITION

There is a significant body of literature describing and evaluating hospital-to-school transition programs (Falvo, 2005). Most program descriptions prepare the child with chronic illness, family, peers, and school personnel for transition back to a school environment after an extended hospital stay (e.g., Bessell, 2001; Case & Matthews, 1983; Prevatt et al., 2000; Sexson & Madan-Swain, 1993; Thies, 1999). Although there are many different approaches, Madan-Swain et al. (2004) described a prototypical three-phase model, wherein phase one involves initiation of community supports, arranging hospital and homebound instruction, and educating peers; phase two involves hospital–school communication, development of an instructional support plan, preparing for absences, and anticipating psychosocial adjustment issues; and phase three involves hospital–school–family follow-up communication. Such a model is effective in facilitating the transition to school for children with chronic illness. However, recent trends in health care service delivery and education systems signal a change in the approach to facilitating hospital-to-school transitions for children with chronic illness (Blank & Burau, 2004).

The evolution of medical care toward increasing outpatient service delivery makes programming for transition from hospital to school more complex (Shaw & Woo, 2008). Rather than a 2- to 4-week hospital stay, a child with cancer may have a 1-day admission followed by 6 to 10 outpatient doctors’ visits over that 2- to 4-week period (Blank & Burau, 2004). The illnesses are still severe, yet a share of the burden of care has shifted from hospitals to parents, schools, and outpatient clinics. This decentralized approach to health care often means that children receiving outpatient care have less access to hospital-based teachers, social workers, and psychologists than children experiencing extended hospital stays (Bowman, 2001). Parents may be required to visit the child’s school daily or more frequently to administer injections, medications, or oversee treatments, or keep the child home altogether. For schools, the transition from hospital to school may be less important than providing responsive and effective education for children with inconsistent attendance and extended homebound periods (Shaw & Brown, 2006).

SUMMARY

Chronic illness is common and has a profound impact on the education of affected children. Previously described transition plans may not be entirely effective because medical service delivery has changed to provide fewer long-term hospital stays and increased outpatient care. This systemic change in health care delivery means that services heretofore provided by the hospital multidisciplinary team may no longer be available, may be reduced in intensity or frequency, or may be relegated to community or school providers through IDEA and/or Section 504 funding sources. The next section describes the needs of children with chronic illness, with a focus on the role of schools in meeting the academic and social needs of chronically ill children in an era of reduced inpatient care. This is followed by a concluding section on educational programming consistent with the current health care system, and hospital to school transition plans that integrate systemic needs of schools and the health care system with the needs of children with chronic illness.

NEEDS OF CHILDREN WITH CHRONIC ILLNESS

Academic Needs

Children with chronic illness have a variety of academic requirements that relate to symptoms and sequelae of the disease or condition. Their ability to successfully reintegrate into the school setting relies on careful planning of the multidisciplinary team (including medical and school personnel and the child’s parents), with attention to the specific academic requirements of the child. There may be cognitive or related side effects caused by treatment of the illness (including
difficulties in attention, memory, and processing speed), such as the cognitive sequelae caused from certain chemotherapy regimens and leukemia treatments (Kretz & McCabe, 2003). Children with insulin-dependent (type 1) diabetes mellitus (IDDM) contend with cognitive deficits associated with hypoglycemic conditions, including reduction in motor speed, slowed processing, visual-spatial deficits, attention deficits, memory difficulties, and increased errors of executive function (Desrocher & Rovet, 2004). Children with IDDM demonstrate lower intellectual functioning and academic achievement scores than controls, and many require special education services (Holmes, Cant, Fox, Lampert, & Greer, 1999). Children surviving a brain tumor face significant learning and neuropsychological difficulties; the most common include difficulties with reading and numeracy, as well as increased social, emotional and behavioral problems (Upton & Eiser, 2006).

In the era of outpatient medical management, many children with chronic illness are prescribed a cocktail of medications to fight ongoing disease, abate symptoms, and minimize related side effects. The side effects from these medications differ greatly and can have an acute influence on the child’s executive functioning, arousal, and learning. For instance, medications to treat seizures may cause sedation, whereas those that treat asthma or cancer may lead to irritability and difficulty focusing (Sessson & Madan-Swain, 1993). Pain, fatigue, nausea, or lethargy resulting from the illness and/or treatment may seriously limit the child’s ability to focus on academics. Behavioral symptoms such as inattention, hyperactivity, or emotional lability may be treated with psychotropic medications in addition to those medications already prescribed for the illness. Because the medical team is not in the school to observe the cumulative effects of multiple medications, it is imperative that school personnel observe the child’s academic functioning and report back to the medical team in a timely fashion. Further assessment by the medical team, in coordination with the school multidisciplinary team, may be necessary to adjust medications, modify treatment schedules, or alter the school day so that the child’s academic performance is maximized.

Another academic concern relates to the child’s ability to return to the school environment after a prolonged absence or while in the midst of an intensive treatment regime. It may be much more difficult to return to school under these circumstances because the child may be significantly behind his or her peers in academic progress, or may be enduring vigorous medical treatments that impair the child’s learning, concentration, and alertness (Madan-Swain, Fredrick, & Wallander, 1999). Indeed, the incidence of school refusal among children who are chronically ill is up to five times greater than the rate among the general population (Shiu, 2001). Under these circumstances, homebound instruction may be necessary until sufficient gains in academic development and/or medical treatment have transpired.

Academic Motivation

A child with chronic illness may suffer lack of motivation in academic and school-related activities for a number of reasons. As mentioned previously, disease symptoms or side effects of treatment regimes can induce fatigue, lethargy, irritability, or other physiological states that reduce motivation. There may also be extenuating risk factors in the child’s life that further reduce academic motivation. For example, children with HIV/AIDS are likely to have one or more parents with HIV/AIDS, may be living with extended family members who are grieving and experiencing loss, and are more likely to be living in poverty (Landau, Meyers, & Pryor, 2006). Given these conditions, the child with HIV/AIDS may be much less able to focus on academic tasks and may view their future as less hopeful, thus reducing motivation to succeed and overcome their medical, psychological, and environmental hurdles.

This suggests that schools can best help children with chronic illnesses by targeting the mediating variables in the child’s environment that affect motivation, while the medical management team
attempts to decrease physiological symptoms from the illness (Sheilds, Heron, Ruberstein, & Katz, 1995). There is little research available on the predictors of academic motivation in children who are chronically ill. However, there is also little evidence to suggest that children who are chronically ill would differ substantially from healthy children in their motivation to succeed academically, with the exception that pain, fatigue, or other physiological states might affect motivation over time. Research with healthy children (with no history of chronic illness) suggests that home and school experiences affect later academic motivation (Luster, Lekskul, & Oh, 2004). Among children born to low-income adolescent mothers, the quality of children’s enrichment experiences in the home prior to schooling is related to their cognitive development, which in turn predicts greater academic competence in school. Greater success in academic tasks predictably leads to increased achievement motivation in the elementary grades (Luster et al., 2004). Hence, it appears that working to create supportive and enriching home environments, and fostering positive parental practices, may help increase the academic motivation of children with chronic illness.

Social and Emotional Needs

The literature is unequivocal that children with chronic illnesses have an array of social and emotional difficulties secondary to their illness and/or extended absence from school, and these difficulties can further exacerbate academic and motivational concerns. Chief among these difficulties are increased behavior problems, especially internalizing problems such as depression and withdrawal (Boekaerts & Röder, 1999); impulsivity and anger control problems related to poor problem-solving skills in relationships (Clark, Russman, & Orme, 1999); increased suicidal behavior (Tate, Simpson, Flanagan, & Coffey, 1997); social rejection, perhaps due to misconceptions among peers regarding the illness and its contagiousness (Sexton & Madan-Swain, 1993); and anxiety over physical changes and appearance related to the child’s body image and fear of peer rejection (Sexton & Madan-Swain, 1993). Poor peer relationships are associated with further stress as frequent absences disrupt friendship formations, reduce opportunity for social support, and make children with chronic illness increasingly vulnerable to other life stressors or secondary illnesses (Shiu, 2001). Peer rejection is associated with increased school absenteeism, which further complicates the problem.

By the time children with chronic illness reach adolescence, their history of rejection and truncated social opportunities unfolds into more serious psychopathology, including depression and low self-esteem (Erickson, Patterson, Wall, & Neumark-Sztainer, 2005). Adolescents with chronic illness are twice as likely to consider suicide and three and one-half times more likely to attempt suicide. They also report more substance use, including cigarettes, marijuana, and illicit drugs (Erickson et al., 2005). By the time they reach early adulthood, most youth with chronic illness achieve fewer developmental milestones, or do so at an older age, than their peers who are not ill, across all domains of development (Stam, Hoffman, Deurloo, Groothoff, & Grootenhuis, 2006).

Despite the bleak social and emotional forecast for children with chronic illnesses, there appear to be a number of resiliency factors that may foster an improved social outlook. Children with chronic illness have been reported as being less aggressive than their peers in the classroom by both teachers and peers, which may be associated with heightened parental monitoring (Gartstein, Noll, & Vannatta, 2000). The coping strategies among children with chronic illness have been identified as being a resilient feature because it has been hypothesized that the children have learned to adjust and manage a chronic, potentially life-threatening illness, and have developed coping tools that enable them to better handle common and illness-related stressors (Hampel, Rudolph, Stachow, Lab-Lenzsch, & Petermann, 2005). Similarly, children who have been hospitalized are more likely to provide altruistic choices on social scenario tasks than their nonhospitalized school peers (Seagle, Jessee, & Nagy, 2002). They are also more likely than their healthy peers to take the perspective
of a person in need (Sterling & Friedman, 1996). Although children who are chronically ill are more likely to miss social opportunities due to absenteeism, or become the target of teasing and bullying due to their physical differences, they are also more likely to exhibit preferred personality qualities, including a less aggressive temperament, flexible coping style, and altruistic leanings. School professionals can capitalize on these resiliency attributes by involving children who are chronically ill in social situations that highlight their strengths and unique gifts.

Adjustment Needs and Attendance

Because of reduced hospital stays and greater use of outpatient medical care, children with chronic illness are increasingly being returned to home and school environments in the midst of their ongoing medical treatment. This places a growing burden on school districts and families to accommodate these youngsters as they attempt to normalize their situation and maximize their academic progress. These trends appear to be widespread and not an artifact of the American or Canadian health care systems. In an Australian survey of parents’ perceptions regarding the role of the school in helping to provide health care to their children who are chronically ill, 48% of parents reported that their child required some form of health care or assistance while at school (Notoras et al., 2002). This included supervising meals (36%), administering insulin (19%), and dispensing nebulizer treatments (19%). Furthermore, 75% of parents believed that special knowledge and skill was required to administer health care to their children who are chronically ill, but 56% of these parents believed teachers and/or teaching assistants lacked the knowledge and skill to care for their children (Notoras et al., 2002). This suggests that schools may be required to provide health care training for teachers and teaching assistants for situations in which the school nurse is unavailable or unable to administer health care in a timely fashion.

Physical Needs. Physical supports for children with chronic illness may involve significant structural and material adaptations, including physical therapy equipment, assistive mobility and communication devices, improved accessibility for individuals with disabilities, and life support equipment. However, some supports are relatively minor in terms of cost and inconvenience, such as providing additional quiet space to complete work, making a cot available for brief naps to overcome the fatigue of a long school day, using partitions to reduce distractions and potentially embarrassing situations from classmates, and having medications delivered to the classroom (or just outside the door) to minimize out-of-class time. Even fairly common disorders such as allergies and asthma may require some physical and academic accommodations, such as reduced activity in physical education classes, or late or extended school day to overcome the fatigue and general malaise associated with those conditions (Bender, 1999).

It is important for school practitioners to understand that the assistive devices and medical technologies that prolong life can also significantly affect the lifestyle of the child and his or her family, and serve as recurring reminders that the child is different than his or her peers (Shiu, 2001). Peers may reject the student if treatments significantly disrupt socialization or if treatments appear extreme and depict the child who is ill as grossly abnormal. It is hypothesized that the severity of the child’s physical disorder has an effect on both behavioral and social adjustment, such that illness characteristics may indirectly affect adjustment by causing increased psychosocial stress (Worchel-Prevatt et al., 1998). These stressors might include fear of relapse, amputation, or seizure, or contending with daily hassles such as failing an assignment or grade, missing school, or being alienated by peers (Worchel-Prevatt et al., 1998).

If the special needs of the student are not planned using a systematic and compassionate approach, the school setting can quickly become associated with social and academic failure (Shiu, 2001). To thwart this failure, it is recommended that the student be involved with all stages of their
academic planning, if possible, and that regular monitoring checkups be conducted with the student to identify any new sources of academic difficulty or social ostracization.

**Programming for an Evolving Health Care System**

The changing face of health care and education requires new methods of service delivery for children with chronic illness. All transition programs should be individualized. However, four common components will be included in nearly all transition programs for children with chronic illness.

**Homebound Instruction**

Due to the change in health care service delivery from frequent inpatient hospital status to predominantly outpatient procedures, children with chronic medical issues spend more time at home than in the past (Weller et al., 2003). Although the responsibilities of school personnel to provide specialized educational services, reintegration/transition assistance, or accommodations for schoolchildren with chronic illness are widely described in the medical and educational literature, homebound instruction, in particular, is rarely addressed in the literature or in state, provincial, or local educational policies (Maccioemi & Ruben, 1989; North Carolina Department of Public Instruction, Exceptional Children’s Division, 2000). Homebound instruction is a system of educating students who are unable to attend school due to illness (mental or physical) or injury (Telzrow, 2001). This involves a certified teacher visiting the student’s home to provide individual instruction. Homebound instruction includes programs that were developed from a patchwork of educational policies, statutory law, and case law, as well as innovative local programs to provide educational instruction for these children in the safety and comfort of their own homes (American Academy of Pediatrics, Committee on School Health, 2000; Madan-Swain et al., 1999; Shaw & Brown, 2006).

Homebound instruction can be an excellent component of a program to assist in the transition of children with chronic illnesses from hospital to school (Blakeney, 1994). However, there are significant barriers to homebound instruction becoming an effective service delivery system. Among these barriers are lack of consistent eligibility criteria, challenges of collaborating with medical professionals, difficulty in managing the academic engaged time of children, high cost to school systems, the requirement of significant parent involvement, low academic motivation of children with chronic health issues, administration and coordination difficulties, and the pedagogic difficulties of teaching children at home. Often, a difficulty with homebound instruction is lack of flexibility in the delivery of homebound instruction services. For example, due to the administrative challenges of having a certified teacher visit the home at least 1 hour per day, many districts require a minimum of 15 days of homebound instruction before they will consider providing services. This lack of flexibility may hinder the transition to school.

Because children receiving homebound services most often receive 1 hour of teacher contact per day, they are expected to keep pace with their peers with extensive individual work. This results in a de facto home schooling situation in which parents provide instruction, support, and supervision of academic work. Because of this additional stress placed on parents, transition programs require a significant parent education and support program. The support may take various forms. For example, providing families with computers with Internet access for a limited time frame can contribute to the effectiveness of homebound instruction, while also reducing parent stress. Sending and receiving assignments and instruction via e-mail allows for an interactive experience between student and teacher without the teacher having to be physically present. Another example of family support is having teachers call students to remind them of their work schedules and to be available to answer...
specific questions. In addition, teachers calling parents to answer questions and make suggestions can provide significant support to parents untrained in pedagogy. Teachers can also hold online chat sessions with the entire class to answer questions and allow the home-schooled child to feel more involved with the class.

**Flexible Attendance**

As students are ready to attend school, flexible school days are important components of the transition (American Academy of Pediatrics, Committee on School Health, 1993). Half days are commonly used for children who have chronic illness (Frieman & Settel, 1994). Children with chronic illness have levels of fatigue, pain, alertness, stamina, and attention that vary from day to day (Mukherjee, Lightfoot, & Sloper, 2000). Although challenging administratively, schools may need to be prepared to provide, for example, homebound services on one day, one-half day of school the next, and a full day of school on the third day (Clay, Cortina, Harper, Cocco, & Drotar, 2004; Tate, 2000). This burden on the schools is minimized through the use of technology. Telephone consultation, e-mail, fax, instant messaging, text messaging, and delivery of assignments via e-mail all can increase instructional flexibility (Shaw & Brown, 2006).

**Differentiated Instruction**

Differentiated instructional strategies are gaining standing as an effective method of addressing individual differences in the classroom (Broderick, Mehta-Parekh, & Reid, 2005). Differentiating instruction can be an especially valuable approach when applied to children with chronic illness. Adapting instruction to student needs, especially when these needs may vary for the student with chronic illness from day to day, is an important aspect of the transition process (Bowman, 2001). The philosophy of differentiated instruction provides an approach to organizing the teaching of children with chronic illness.

The academic challenges for children with chronic illness will be case and disease specific, requiring an individualized approach (Shapiro & Manz, 2004). There are a number of excellent encyclopedias compiling the more common childhood illnesses and disorders that school professionals will likely encounter (see Fletcher-Janzen & Reynolds, 2003; Phelps, 2006). School professionals should complete their own review of the literature pertaining to the child’s illness, preferably before communicating with the child’s physician or discharge coordinator. This will allow the school professional to alter the instructional content, process, product, and learning environment based on the daily formative assessment of the children to best meet their educational needs.

**Social Support and Affective Issues**

When youth were asked about their perspectives on their illness and overall adjustment, they reported that social support was a highly valued and important component of managing their illness (Lightfoot, Wright, & Sloper, 1999). Although support can be formal or informal, it was most likely to be informal, including parents, teachers, and close friends (Kyngäs, 2004). Although youth reported that social support was highly valuable, they acknowledged that they are excluded from social opportunities due to treatment, personal care activities, fatigue, or transportation problems (Lightfoot et al., 1999). Students described social support from fellow sufferers with similar chronic conditions as particularly valuable, especially when the peer was close in age and severity of illness (Kyngäs, 2004). Many students reported developing special relationships with teachers that they described as “valuable.” However, students also reported significant variations in teachers’ responses,
indicating that some teachers were more empathetic and seemed to “understand” the student’s plight, whereas other teachers lacked knowledge about the student’s health needs or were unsympathetic and inflexible (Lightfoot et al., 1999; Mukherjee et al., 2000). In terms of peer relationships, youth with chronic illness reported being ignored by peers, being the subject of curiosity and excessive questioning, and being verbally abused. Only one third of respondents indicated that they had no problems with peers subsequent to becoming ill (Lightfoot et al., 1999).

Affective issues play a large part in the effectiveness of children’s transition from hospital to school. Mental health counseling is often an integral component of the transition (Chesson, Chisholm, & Zaw, 2004). Children recovering from chronic illness may experience lack of academic motivation, frustration, an external locus of control, and feelings of helplessness. Yet, counseling is not always necessary. Many children manage the emotional adjustments of chronic illness with great skill. Nearly all children with chronic illness experience some feelings of loss of control (Bessell, 2001). Sometimes this is temporary, whereas at other times loss of control can lead to feelings of hopelessness and an increase in depressive symptoms (Chesson et al., 2004). An important domain in any transition plan is to provide a method to make social support available.

**CONCLUSION**

The nature of transition from hospital to school for children with chronic health problems has evolved in recent years. The need for cutting medical costs and the improvements in medical treatments and therapies have dramatically reduced the number of days of hospitalization for children with chronic illness. Only the most unstable patients received therapies on an inpatient basis. The implications of this shift in medical care delivery are that the traditional emphases in transition programs require modification. Schools will need to be more flexible in designing individualized education plans that adjust to the child’s medical regimen, and that target the child’s academic, socioemotional, and physical needs. Regular monitoring by the multidisciplinary team will help ensure that children with chronic illness do not fall further behind in their academic development, or suffer undue social and emotional consequences secondary to the illness and/or seclusion from school.

Educators developing transition plans for children with chronic illness would benefit from considering the following issues:

- Develop strong working relationships between school and health care systems. Specifically, programming is benefited when multidisciplinary teams are knowledgeable regarding the course of illness, treatment regimen, and potential effects of medications.
- Students are individuals and not diagnoses. Family factors, temperamental factors, social support, and many other factors mean that students with the exact same medical condition may respond and adjust very differently.
- Multidisciplinary teams should continuously evaluate the transition program. By doing so, sudden changes in attendance, academic performance, or social adjustment can be addressed quickly.
- Support parents. The increase in outpatient services puts enormous burdens on families. Multidisciplinary teams can help make challenging programming issues (e.g., homebound instruction) more seamless, coordinated, and less burdensome to parents.
- Listen to the child. Some children enjoy educating teachers and peers about their illness. This can be therapeutic for the child and edifying for the child’s class. However, other children with chronic illness want to be treated like everyone else and shun unsolicited attention. When possible, privacy wishes are to be respected.
APPENDIX

Information for Transition Support

WEB SITES

www.lehman.cuny.edu/faculty/jfleitas/bandaides/index.html
Bandaides & Blackboards is an interactive Web site for children with chronic illness. Children have access to monitored chat rooms; art, poems, and personal experiences; and information from peers and experts concerning coping with chronic and severe illness.

www.starlight.org/site/c.fuLQK6MMIpG/b.1038035/k.BDF4/Home.htm
The Starlight Starbright Children’s Foundation offers a rich Web site with several programs and resources for transition to school. DVD, CD-ROM, and print materials for children, parents, and professionals are available. All materials are low cost, high quality, and engaging.

BOOKS


The most complete book concerning the role of school and pediatric school psychologists for intervening on behalf of children with chronic illness.


A compendium of common (and not so common) childhood disorders that includes definitions and characteristics, prevalence, treatment, and expected outcomes.


Organized by significant childhood illnesses (e.g., cancer, epilepsy, kidney diseases), this handbook is useful in highlighting how collaboration among multidisciplinary teams across settings (hospital, school, and home), described in the first chapter as the multiscystemic framework, can maximize intervention outcomes.

REFERENCES


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