

EDUCATING CHILDREN WITH CHRONIC ILLNESSES

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Abstract

Children and adolescents with chronic illness are at the intersection of the health and education systems. Unfortunately, typical educational programs and policies are not designed to support students battling chronic illness. Examination of socialization, psychological impact, academic achievement, motivation, absenteeism, a parent's role, and district support provides helpful information for educators who wish to create supportive environments for students with chronic illness.

I Just Wanna Be a Kid Again

Lyrics by John Finney

Music by Matt Wahl

The days are long the nights are longer. I wake to see if hopes arrived. Sometimes weak and sometimes stronger. Sometimes surprised that I survived.

But I just wanna be a kid again and have my body feel good like it did back then. Arms and legs would be strong and I'd run and play. Leave the pain and fear for another day. And I could do all those things that I did when I could just be a kid.

I close my eyes and I can see the way that I used to be. The memory's like a warm soft glow, reliving the life I used to know.

But I just wanna be a kid again and have my body feel good like it did back then. Arms and legs would be strong and I'd run and play. Leave the pain and fear for another day. And I could do all those things that I did when I could just be a kid.

And I've learned things that I never knew, accepting what this new me can do. I'd live this life a day at a time. But I'm lucky, I feel love and it's mine.

But I just wanna be a kid again and have my body feel good like it did back then. Arms and legs would be strong and I'd run and play. Leave the pain and fear for another day. And I could do all those things that I did when I could just be a kid.

I'd love to do all those things that I did...and I could just be a kid.

<http://www.mattwahl.com/joshuas-camp-song/#>

Chapter 1-Introduction

Overview:

A large and growing number of students have chronic illnesses that affect their emotional development, physical development, academic performance, and family interactions. A significant common error in educating those students is assuming that the outcomes of their illnesses are solely medical. The wide-ranging effects of many chronic illnesses can be addressed by medical professionals, school professionals, and families. So far, knowledge of medical issues typically is not part of the curriculum for training teachers, psychologists, or other educators. The gap between professional training and the need for knowledgeable professionals with regard to medical issues is wide. Without changes in pre-service and in-service training, this gap is likely to grow wider.

Research Question:

How does chronic illness in children affect socialization, motivation, and academic achievement in schools?

In what ways can educators support children living with chronic illness throughout their school experiences?

Significance of Study:

Approximately 20% of school-age children in the United States suffer from a chronic illness that affects their performance in school (McClaskey, 2010). Each year, 6.5% of students experience chronic illness to the point that it affects their school performance. The primary error that educators make in addressing those students' needs is assuming that the effects of the illness are exclusively medical. However, chronic illnesses also affect students' emotional and physical development, academic performance, peer relationships, and family interactions.

Chronic illnesses are long-term or permanent medical conditions that have recurring effects on everyday life. Common chronic illnesses include asthma, cancer, diabetes, eating disorders, sleep disorders, and traumatic brain injury. Less common, but no less severe, illnesses include sickle cell disease, seizure disorders, and HIV/AIDS (Shaw, Glaser, Stern, Sferdensch, & McCabe, 2010). The number of students who have chronic illnesses is growing because of medical advances that have increased the number of diagnoses. The life expectancy and functional abilities of children with many different chronic illnesses (e.g., leukemia) has also increased because of medical advances. What may have once been a terminal illness is now considered chronic. However, all chronic illnesses among students affect those students, their families, and schools.

Outline of Literature Review:

First of all, many chronic illnesses and injuries result in cognitive impairments. These impairments include disease or injury itself, stress or anxiety from living with the disease, or as a result of the medications used to treat the symptoms. Many medications cause side effects that significantly affect learning, including: sedation, restlessness, irritability, lethargy, fatigue, difficulty focusing, pain, nausea, emotional problem, tremor, and poorly coordinated muscle movements. In addition to academic difficulties, students with chronic illnesses can struggle with mental, social, and emotional problems that affect their school experience and may make it harder to engage socially or maintain relationships.

Next, students may be hesitant to participate in activities with friends for physical reasons or because they feel too different or self-conscious. They may need privacy to deal with physical symptoms, which can be hard to achieve in school. Chronic illness also can prevent or hinder students' participation in extracurricular activities, which promote positive academic and social-

emotional outcomes. The differences and limitations can be particularly difficult for youths who already feel pressures to fit in. The resulting sense of frustration or social isolation can add to any mental health problems that are associated with the primary illness.

Lastly, students with chronic illnesses may also suffer from a lack of motivation and refuse to go to school. Refusal to attend school may be greater in students who have a chronic illness.

Definition of Terms:

Cognitive Impairment- Cognitive impairment is the condition when an individual has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe (Cognitive impairment: a call for action, Now! www.cdc.gov/aging/healthybrain/index.htm).

Chronic Illnesses- Chronic illnesses are long-term or permanent medical conditions that have recurring effects on everyday life. Common chronic illnesses include asthma, cancer, diabetes, eating disorders, sleep disorders, and traumatic brain injury. Less common, but no less severe, illnesses include sickle cell disease, seizure disorders, and HIV/AIDS (Shaw, Glaser, Stern, Sferdensch, & McCabe, 2010).

504 Plans- 504 Plans help children with special health care needs fully participate in school. Usually, a general education student uses a 504 plan when he or she is not eligible for special education services. A 504 Plan outlines required accommodations related to the child's disability so that he or she may participate in the general classroom setting and educational programs (PCD Foundation, 2011).

Peer Victimization- the experience among children of being a target of the aggressive behavior of other children, who are not siblings and not necessarily age-mates (Sentenac et al. 2012).

Coping Mechanism- an adaptation to environmental stress that is based on conscious or unconscious choice and that enhances control over behavior or gives psychological comfort.

Portals- patient portals combine personal health records with electronic health care records as a tool for patients and families to use when not in the hospital (Britto, Hesse, Kamdar, and Munafo, 2013).

Intrathecal Administration- Intrathecal drug administration involves the introduction of a therapeutic substance by injection into the subarachnoid space of the spinal cord (Jain, 2013).

Parent-child Shared Management Tool- An online tool used to help with the understanding and outcomes of a patient's medical procedures (Britto, Hesse, Kamdar, and Munafo, 2013).

Chapter II: Literature Review

The survey of literature related to children with chronic illness reveals the importance of transitioning from being a patient to becoming a student.

Socialization in the School Environment

Wideman-Johnston (2011) stated that the integration of students with chronic illnesses into the traditional school setting provides them with the opportunity to participate in a community beyond being a patient. The notion that attending school provides far more benefits than simple academic development is well-known. Consistent school attendance offers opportunities for peer relationships, support, and contributions to an individual's self-worth (McCabe and Shaw, 2008). Research supports that when examining the needs of students with chronic illness, inclusion with conventional life experiences, such as attending traditional school settings, is beneficial for students with chronic illness.

According to Sentenac, Arnaud, Gavin, Moicho, Gabhainn, and Godeau (2011), peer victimization is linked to appearance or behavior, especially in children having difficulty developing relationships and social networks. This may lead to the idea that children with chronic illnesses are at a higher risk of being bullied by peers because of their mannerisms, difficulties with mobility, speech patterns, or special care needs. While anti-bullying programs in schools have shown to be effective, little is known about the impact of these programs on children with chronic conditions. Sentenac, et al. (2011), found a significantly higher level of peer victimization among children with some types of chronic diseases compared to healthy children. Between 1991 and 2010, Sentenac, et al. conducted 59 studies related to bullying, 90% of which were published in the last decade. In 31 studies, participants were sampled in schools,

whereas the other studies were based on population-based samples of children with specific conditions extracted from general, household, and hospital. In these studies, the sample sizes ranged from 19 to 101,778 children. The age range of children surveyed were between the ages of 5-17 years. Both genders were considered in all studies except one, in which only boys were included (17). Of the 59 studies conducted, a large range of chronic conditions was represented: psychiatric diagnosis, learning difficulties, speech and language disorders, physical and motor impairments, chronic diseases, and weight status (Sentenac et al., 2011). Six studies were based on a not-specified diagnosis assessment such as chronic conditions, disabilities, and special health care needs.

Throughout the research of Sentenac, et al. (2011), various methods of assessing levels of peer victimization were used. A definition of peer victimization was given to the respondent in four studies. Twenty-seven studies used 1 of 14 validated questionnaires identified in this review; non-validated questions were used in 21 studies; peer victimization questions were taken from a nonspecific, existing questionnaire in another six; while interviews were used in five studies. The result of the study found a significantly higher level of peer victimization among children with some type of chronic disease compared to healthy children (Sentenac et al., 2011).

Children and parents both report deficits in social competence in children with chronic illness. Precisely, the size of -0.34 for child-reported and -0.51 for parent-reported social competence were medium to large, while peer and teacher reports were non-significant (Carter, Martinez, and Legato, 2012). Carter, Martinez, and Legato (2012) studied the parent reports of social competence in younger children at different developmental stages. They implemented the Achenbach Child Behavior Checklist containing several subscales related to social skills, using only the social competence subscale because it measured children's positive interaction skills.

They also examined several different sources of variation in social competence effect sizes, including chronic illness type, demographics, informants, and measures used. These analyses tested whether the effect varied according to these variables and found no significant associations. Another point is the argument that parent reports may be more accurate for younger children in determining social ability. Carter et al (2012) reports that parent reports may be more accurate for younger children whose social interactions are still closely observed by their parents as opposed to adolescents who develop close, intimate relationships with peers. Carter et al. (2012), suggests that social skills prevention and interventions are necessary for some children with chronic illness. Carter et al. (2012) recommended that a comprehensive assessment of social competence, including parent and child perspectives, should be used to guide referral decisions.

Psychological Impact

Pao and Ludi (2011) asserted that approximately 20% of children with chronic medical conditions have behavioral and emotional symptoms. These symptoms are normal responses to illness and hospitalization, but when they become compulsive and impair a child's development, early intervention and even prevention are needed. Symptoms of depression and anxiety, especially those evidenced by insomnia, loss of appetite, and fatigue, are common in chronically ill patients and can be over looked or undertreated. Depressive symptoms add to the burden of illness and have been associated with poorer medical outcomes, repeated hospitalizations, and disease-related complications in medically ill patients (Pao and Ludi, 2011). Depression symptoms have been found to be as high as 68% in pediatric patients with serious medical illness and focus on the cognitive symptoms of depression, such as poor concentration, low self-esteem, feelings of guilt or of being a burden to others, and any suicidal thoughts (passive or active). Pediatric patients with a history of multiple hospitalizations commonly experience anxiety. A

number of factors can contribute to the presence of anxiety symptoms: illness-related biological mechanisms, a response to diagnosis or being in the hospital, genetic and psychosocial causes, or a combination of all of these. Pao and Ludi (2011) suggests some medications may be needed for children with chronic illness to treat depression and anxiety to improve their overall quality of life.

According to Piquart (2012), children with chronic illnesses or disabilities feel worse about themselves than their healthy peers and often feel different from their peers while experiencing peer rejection. Piquart (2012) studied 58,281 children and adolescents with chronic illness. The largest subgroups had obesity (n=10,220), arthritis/rheumatism (n=7620), diabetes (n=4443), cancer (n=3887), and asthma (n=2890). The mean age was 12.30 years with 52% being girls and 37% were members of ethnic minorities. The mean duration of the chronic illness was 7.01 years. A comparison of 21 diseases showed significantly reduced levels of self-esteem in children based on more than 600 studies. Children with a chronic physical illness were found to have lower levels of self-esteem than healthy peers, and most differences were small (Piquart, 2012).

According to Sein (2001), one of the main aims of management for a child dealing with a chronic illness should be to help cope with the reality of having an illness. Self-esteem is an important aspect of the coping mechanism and it could be promoted through intellectual and creative skills as well as through physical activities such as play and sports. A supportive atmosphere which encourages expression of feelings is also a powerful coping mechanism. Relationships, such as those with peers, may be critical in coping with long-term illness. Close peer relationships are an important source of support. The development of emotional and behavioral problems in children and adolescents are likely to impact academic performance as

well (Chesson, Chisholm, Zaw, 2004). It has been recognized that children's problems in one sphere of life, for instance at home or in school, cannot be treated in isolation (Chesson, Chisholm, Zaw, 2003). Pediatric specialists and school counselors should collaborate more closely because they deal with common psychosocial issues. Resources may be used more effectively, through joint programs, for instance, regarding approaches to patient education. Greater contact between pediatricians and school counselors may also be beneficial (Chesson, Chisholm, Zaw, 2003).

Academic Achievement, Motivation & Absenteeism

Crump, Rivera, London, Landau, Erlendson, and Rodriguez (2013) suggested that chronic health conditions in early life adversely affect school performance. They studied the number of full day school absences per year, based on school attendance records and California Standards Tests (CST) for English Language Arts (ELA) and math from the 2008-2009 and 2009-2010 school years. They also measured academic performance in three ways: CST performance levels divided into "basic or below" versus "proficient or advanced", CST scores categorized into five ordered performance levels (advanced, proficient, basic, below basic, and far below basic), and numerical CST scores converted into z-scores, indicating the number of standard deviations above or below the mean CST score for a particular grade and school year. The results indicated that chronic neurodevelopmental and seizure disorders were associated with low school performance among children and youth, regardless of ethnicity, socio economic status, or grade level (Crump et al., 2013). The authors recommended educational, medical, and social support interventions at early ages to reduce gaps from these conditions.

Thies (1999) noted that children and adolescents with chronic illness experience more academic difficulty than their healthy peers. Forty-five percent of students with chronic illness

report falling behind in their school work, leading them to dislike school. Fifty-eight percent of students with chronic conditions regularly miss school, and 10% miss more than 25% of the year. According to Thies (1999), children who miss more than 30% of days within a grading period are more likely to fail. Main reasons for absenteeism include minor medical problems, such as a cold, which can complicate the health of a child with asthma or on chemotherapy, medical appointments, and restrictions on activities. Interestingly, Thies (1999), states the total number of days absent is not directly related to academic achievement, nor is illness severity. Rather, the pattern of absence and the chronicity of the condition itself makes it difficult for these children and adolescents to achieve their potential. The combination of chronicity, absence, and side effects of illness and treatment are subtle, but the increasing effect is potentially damaging. Falling behind academically leads to catching up, and catching up takes time away from keeping up. Effects of treatment for leukemia are the subject of significant interest. Some children receive prophylactic CNS therapy, which may include intrathecal administration of chemotherapy, radiation of the brain and spine, or both. Three years after diagnosis, treated children scored lower on tests of reading, spelling, and mathematics than controls. Up to 14 years post treatment, shortfalls in academic achievement still were noted. Deficits in verbal coding, memory, and attention were especially prominent (Thies, 1999).

Children with chronic illness are absent from schools for an average of 16 days a year compared to around three days absent for healthy children (Shaw & McCabe, 2008). However, some chronic disorders take a more intense 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 three years that follow (Shaw & McCabe, 2008).

In Table 1, some examples of chronic childhood illnesses, as well as corresponding treatment regimens, side effects, and average 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. 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 (Shaw and McCabe, 2008).

Examples of Chronic Childhood Illnesses, Treatment Regimens, and Range of School

Absences

Illness	Treatment	Side Effects of Illness and/or Treatment	Average Range of School Absence	References
Asthma	Inhalant medication therapy (beta-agonists, corticosteroids); leukotriene modifiers; antihistamines	Malaise; drowsiness and fatigue; sleep loss; hypoxia; temporary fine-motor dysfunction after using beta-agonists	12-36 days	Bender (1999)
Cancer	Chemotherapy; radiation therapy; surgery; bone marrow transplants; medication	Nausea and gastrointestinal problems; fatigue; hair loss; pain; anemia; increased infections; skin irritation; loss of appetite	Dependent on nature of cancer and treatment; average from 25 to 80 days	Vance & Eiser (2001)
Cystic Fibrosis	Nutrition monitoring, including high calorie diet; growth hormone; pancreatic enzymes; drugs for respiratory symptoms; chest	Stunted height and weight growth; pulmonary difficulties associated with excess mucosa; decreased appetite; fatigue; body image problems related to stunted growth	Wildhagen et al. study: 19.5 days	Strawhacker & Wellendorf (2004); Wildhagen et al. (1996)

	physiotherapy			
HIV Infection	Antiretroviral medications (often used in combination therapy with at least three drugs)	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)	Cohen et al. study: 10–40days; 3% were too ill to attend school, and another 5% were home schooled	Cohen et al. (1997); Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children (2006a, 2006b)
Insulin-dependent diabetes mellitus	Insulin monitoring and injections; dietary management; exercise	Acute hypo- or hyperglycemia (ketoacidosis), affecting attention, memory, learning, and processing speed	14 days	Desrocher & Rovet (2004); Holmes et al. (1999)
Traumatic brain injury	Hospitalization and treatment of open or closed head injury; pain management; cognitive, behavioral, and socio-emotional interventions	Broad range of deficits, including speech and motor functioning, memory, sensory processing, cognition, and socio-emotional functioning	Mean length of hospitalization: 46 days; additional school absence may be required for rehabilitation	Clark et al. (1999)

*Mean school absences for healthy children are approximately 3– to 3.5 school days a year (Shaw & McCabe, pp.75, 2008).

Children with chronic illness have a variety of academic requirements and their ability to successfully reintegrate into the school setting relies on careful planning of the 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 from certain chemotherapy regimens and leukemia treatments (Shaw & McCabe, 2008). 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 (Shaw & McCabe, 2008).

A child with chronic illness may suffer lack of motivation in academic and school-related activities for a number of reasons. Disease symptoms or side effects of treatment regimens 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. 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 center of their ongoing medical treatment (Shaw & McCabe, 2008). 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. 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 (Shaw & McCabe, 2008). This included supervising meals (36%), administering insulin (19%), and dispensing nebulizer treatments (19%). Furthermore, 75% of parents believed that special knowledge and skill were required to administer health care to their children who were chronically ill, but 56% of these parents believed teachers and/or teaching assistants lacked the knowledge and skill to care for their children (Shaw, et al. 2008). 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.

Creating Supportive School Environments for Students with Chronic Illness

Irwin and Elam (2011) feel educators are among the group of professionals responsible for ensuring quality of life experiences for students living with chronic illness, however typical educational systems and policies are not designed to lend support to students battling chronic illness.

Schools face challenges incorporating children with different illnesses into the classroom. [...] Most children spend nearly half their waking hours with their teacher and school personnel. Yet most educators have had little training about the needs of children with medical conditions in the classroom (Irwin and Elam, 2011, p.68).

With limited knowledge and resources, well intended teachers and administrators might respond to severe health episodes with impromptu plans, inadvertently creating educational barriers, eliminating the possibility of a reasonable educational experience for students with an illness. Many children with chronic illness do not immediately fit into any pre-established programs in schools.

Even when these children return to the classroom, the educator's lack of familiarity with the educational implications of the child's disease creates further challenges. Most often, those charged with the responsibility of properly educating children with chronic illness are unaware of the complexity of academic issues that have been introduced to the child's classroom experience. Many children with chronic illness have lower achievement test scores than their healthy peers, even without evidence of cognitive impairments (Irwin & Elam 2011). However, many chronic illnesses actually do result in cognitive impairments. Evidence exists that teachers may attribute problems to the illness, thus allowing the impaired learning to continue without further intervention, deepening frustration and failure for the student (Irwin & Elam, 2011).

To maximize attendance and ensure educational growth, many of these children require coordinated school interventions. While in some cases a specific special education plan may be appropriate, some of the traditional special education placements are not always ideal for these children. Rather than placing students into special education programs designed for children with learning disabilities and developmental disabilities, schools can think differently about children with chronic illness by designing programs for these children that integrate their health and educational needs (Irwin & Elam, 2011).

A Parent's Role

Parents play a key role in advocacy for their children, not just advocacy in the school setting, but also in healthcare settings. Because parents are the most knowledgeable about the needs of their children, equipping them with resources and channels for advocacy will strengthen the support network for children with chronic illnesses.

Most care for children with chronic illnesses takes place in the home and requires parents/caregivers to be prepared and self-confident in their ability to meet the physical, social, and psychological challenges they face in managing their child's condition. Parents typically receive little preparation for the ongoing process of goal setting and bringing their child into shared care (Kieckhefer, Trahms, Churchill, & Simpson, 2009).

Sein (2001) found that a high proportion of parents (76%) expected the psychosocial aspects of care to be covered by the physician, but the parents rarely raised the issue themselves and only in one fourth of the visits were the issues actually discussed. They found that when these parental expectations were not met, this was associated with a greater degree of dissatisfaction in the parents. Finally, Sein (2001), notes that while 80% of the discussions on

physical symptoms were recorded in the notes, only 25% of the discussions on psychosocial aspects were recorded. The parents rarely raised psychosocial issues during the visit due to the fact that they did not feel the physicians would be interested in those issues or, even if they are, that there may not be a “solution” offered. Sein (2001) argued that the management of chronic illness should be family-oriented and should not just deal with the management of the physical aspects of the illness. The family’s coping and adaptation mechanisms should be acknowledged in the light of the family’s attempt to achieve a balance without comparison to families that do not deal with chronic illness. Sein recommended that support from social structures and agencies should be made available when necessary.

Britto, Hesse, Kamdar, and Munafo, (2013) suggested the use of patient portals which may be developed and customized for specific health conditions. Accessible through any Internet-enabled computer, portals provide access to elements of medical records, including demographic and contact information, test results, medications, and secure messaging with care provider. The importance of being able to communicate electronically with health care providers enables parents and children to have the convenience of creating a sense of control and independence while attending school. Britto, Hesse, Kamdar, & Munafo, 2013 demonstrated that portal benefits removed barriers to communication, reduced hassles, maximized convenience, provided a sense of control and independence, reduced anxiety, and provided reassurance. Electronic communication encouraged caregivers to ask non-urgent but important questions. Parents no longer needed to depend on healthcare providers to interpret laboratory results creating more control and security while reducing anxiety. Electronic health care tools, specifically portals, have numerous benefits for the management of chronic illness (Britto, Hesse, Kamdar, & Munafo, 2013).

In the study by Kieckhefer, Trahms, Churchill, Simpson, 2009, the sample consisted of 129 parents of children with chronic illness. Forty-three percent of the parents' children were female. The study participants reported that their children had more severe chronic conditions that more often affected their ability to perform tasks. Parents in the sample were more highly educated, with 82% having more than 12 years of education. Kieckhefer, Trahms, Churchill, Simpson, (2009) found the potential usefulness of a parent-child shared management online tool. The tool demonstrated adequate psychometric properties and appears to have relevance to a broad spectrum of parents with children having chronic illnesses (Kieckhefer, Trahms, Churchill, Simpson, 2009). The current study indicated parental desire, knowledge, and actions that may be differentially improved. Significant positive relationships between parent-child shared management, self-efficacy, and coping are consistent with an assumed view that all three are worthy of support.

Teacher-District Support

The American School Counselor Association's (ASCA) position statement indicates that the professional school counselor advocates for students with special needs and is the one responsible for providing information to school personnel. ASCA's statement clearly represents the importance of a school counselor's role in supporting students with chronic illness. Regarding the specific types of chronic illnesses, counselors report working with students who have diabetes (60%), seizures (51%), asthma (48%), Crohns/IRB (40%), and cancer (38%) (Hamlet, Gergar, & Shaefer, 2011).

The ASCA has outlined the action/interaction strategies in regards to collaboration, educational interventions, the use of 504 plans, and written protocols to follow when a student is diagnosed with a chronic illness. Collaboration was noted as an action strategy that counselors

frequently used, although they could not always access in-school professionals as often as school psychologists and other professionals. Educational strategies to facilitate accommodations, homebound instruction, summer sessions, and other interventions are implemented by school personnel or medical professionals as often as possible. Educational interventions are implemented through a variety of methods, including collaboration with teachers, and medical health professionals were mentioned as action options. The educational options available for children with chronic medical conditions include regular education with accommodations, homebound instruction, on-line courses, tutoring during summer sessions, and correspondence courses. Educational interventions are generally followed when action

Table 1. Percentage of Counselors (n=82) Using Specific Educational Interventions for Children and Youth with Chronic Medical Conditions	
Educational Interventions	% who have used
Regular education	
With accommodations	84%
Homebound instruction	67%
Regular education	51%
On-line courses	13%
Tutoring during summer Session	11%
Summer session courses	10%
Correspondence courses	4%

personnel or medical professionals as often as possible. Educational interventions are implemented through a variety of methods, including collaboration with teachers, and medical health professionals were mentioned as action options. The educational options available for children with chronic medical conditions include regular education with accommodations, homebound instruction, on-line courses, tutoring during summer sessions, and correspondence courses. Educational interventions are generally followed when action

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According to Hamlet, et al. (2011), however, 68% of the counselors reported that their school does not have a written protocol to follow after a student is diagnosed with a chronic illness. Counselors also identified a need for written protocols for student re-entry; yet, 78% of counselors noted that their school does not have a reentry program for students. Other limitations included unclear policies or procedures for confidentiality, challenges in meeting the needs of the whole child, and the lack of opportunities to collaborate with health care professionals.

According to Duggan, Medway, and Bunke (2004), 76% of teachers in the Southeastern United States have taught a chronically ill student, only half of these teachers had been trained to do so, and less than one in ten had received enough training to earn certification. Nearly three in

four teachers felt unprepared to teach students with chronic illnesses and, with the exception of some exposure to first aid procedures, these teachers lack any background with healthcare procedures for students with chronic illness. Studies have shown that teachers want practical information, additional training in teacher education programs as well as experience on the job, and specific information about working with the families of chronically ill students and medical personnel (Duggan et al., 2004). In-service training programs for school personnel, health education for peers, preventive and early intervention techniques, and family and community involvement are examples of services that could be developed to meet the needs of students with chronic illnesses (Peebles-Wilkins, 2006).

Teachers' lack of information and understanding of the impact of childhood chronic illness is a prevalent problem that can result in inaccurate appraisals of a child's symptoms as well as his or her academic and social skills (Clay, Cortina, Harper, Cocco, & Drotar, 2004). For this reason, there is a general consensus that the dissemination of information to teachers- along with open communication between parents, the health care team, and school personnel- are needed to increase the positive adaptation of chronically ill children in the classroom. Clay, Cortina, Harper, Cocco, & Drotar, (2004) used a survey to examine school personnel's attitudes toward and experiences with student substance use, emotional problems, and behavioral problems. The School Health Questionnaire was developed for this study to assess school personnel's training, knowledge of, and experience with children with chronic illness. Nearly every respondent reported knowing a student with a chronic illness (98.7%, n=467). A significant number of respondents (43.4%, n=454) also reported feeling moderately to very responsible for dealing with a child's chronic illness as it pertained to the student's education. Most respondents were specifically concerned with a student's absenteeism (21.9% of

responses), fatigue (13.1%), poor concentration/daydreaming (11.5%), and failure to complete assignments (11.3%). However, 59.4 % (n=446) of school personnel reported receiving no academic preparation regarding the experiences of children with a chronic illness. Only 36.1% (n=415) of the respondents reported receiving any formal educational programs about childhood chronic illnesses issues in the workplace.

The results of this study revealed that nearly all school respondents reported knowing a child in their school with a chronic medical condition. Most frequently reported conditions were asthma, diabetes, epilepsy/seizure disorder, and cancer, all of which have a significant impact on children's social and academic functioning at school. The findings from this survey verify a lack of training among some American education programs regarding the needs and experiences of children with a chronic illness. Nearly 60% of respondents reported no academic training and 64% reported no training in the workplace. Both children and their parents with chronic illness have emphasized the importance of teacher knowledge about chronic illness to the success of the child in school (Clay, Cortina, Harper, Cocco, Drotar, 2004).

Chapter III: Results and Analysis Relative to the Problem

Socialization in the School Environment

Children who have a chronic illness or condition often feel "different," socially isolated, and restricted in their activities. They may have problems in school and feel overprotected by caregivers. They may experience recurrent fear and pain. When these emotional difficulties are not dealt with, they can lead to anxiety, sadness, withdrawal, rebelliousness, or a decreased interest in school.

The social isolation experienced by students with chronic illness creates challenges for social interaction upon returning to school. Student absenteeism and feelings of discomfort are among the factors contributing to social isolation; the constant battle of trying to keep up with lessons and assignments adds further social stress. The psychological repercussions of chronic illness lead students to constantly compare themselves to their healthy peers, continuously seeing an imbalance in their capabilities and difficulty relating to others (Wideman-Johnston, 2011, McCabe and Shaw, 2008, Sentenac, et al.,2011, Carter, Martinez, and Legato, 2012).

Psychological Impact

Researchers have concluded that chronic physical diseases are associated with reduced self-esteem. As self-esteem increases with positive experiences, those working with children with chronic illnesses should promote experiences of success and positive peer-relations, which are important sources of self-esteem. In addition, special prevention and intervention programs aimed at providing realistic information about the chronic illness, enhancing social competence, and reframing stressors has been found to increase the self-esteem of children and adolescents with chronic illnesses (Chesson, Chisholm, Zaw, 2004, Pao and Ludi, 2011, Pinguart, 2012, Sein, 2001).

Academic Achievement & Absenteeism

Children with chronic illness exhibit school-related problems, as a result of psychological well-being, interaction with peers, academic performance, and higher absenteeism. Inability to attend school may lead to decreased self-esteem and hopelessness about the future. Specific aspects of the illness or its treatment, the child's emotional response to the illness, prolonged absence, and learning problems may influence school functioning. Attitudes of parents, teachers, other school personnel and the health care team, combined with the inability of the school, to provide necessary daily health care services may seriously affect successful school re-entry. School psychologists potentially play an important role in maximizing the school success of children with chronic illness as they monitor their educational functioning (Crump, Rivera, London, Landau, Erlendson, & Rodriguez, 2013, Irwin & Elam, 2011, Shaw & McCabe, 2008, Thies, 1999).

A Parent's Role

Chronic illness has been described as a diagnosis “which affects the whole family.” When a family is vulnerable, secondary problems are more likely to arise. Communication difficulties within the family, alongside family conflict, may lead to increased risk of young people developing psychosocial problems. A well-functioning family helps to minimize adverse psychosocial aspects of illness Britto, Hesse, Kamdar, and Munafo, 2013, Kieckhefer, Trahms, Churchill, Simpson, 2009, Sein, 2001).

Most of the care for children with chronic illnesses takes place in the home and requires parents to be prepared and self-confident in their ability to meet the physical, social, and psychological challenges they face in managing the child's condition (Kieckhefer, Trahms, Churchill, Simpson, 2009). Healthcare systems provide expert care for the child's medical needs and medication specific education, but parents typically receive little preparation for the ongoing

process of goal setting and bringing their child into shared care (Britto, Hesse, Kamdar, and Munafu, 2013, Kieckhefer, Trahms, Churchill, Simpson, 2009, Sein, 2001).

Teacher-District Support

To strengthen the achievement of students with chronic illnesses, educators need to provide students with learning opportunities that are applicable to their lives. Offering students opportunities to improve communication, engage in problem-solving, think critically, resolve conflicts, and utilize coping mechanisms are necessary not only to functioning within society, but also for coping with a chronic condition. Students with chronic illnesses have daily experiences quite different from their healthy classmates. Often, their time is filled with medical procedures, medications, doctor and hospital appointments, alternate nutrition requirements, and the physical symptoms and effects of the illness itself (Clay, Cortina, Harper, Cocco, Drotar, 2004, Duggan, Medway, and Bunke 2004, Hamlet, Gergar, & Shaefer, 2011, Peebles-Wilkins, 2006).

To support students in these situations, teachers can help children access resources and develop skills that promote and form relationships with other students with chronic illness to maximize collaboration and a sense of belonging in a community. Without the implementation of accommodations for students with chronic illness, the school environment can rapidly become a place where struggles with academic progress, peer relationships, and psychological failures emerge. Hamlet, Gergar, and Schaefer (2011) asserted that educating the whole child will provide students with an educational community that has the resources and personnel to meet their academic, social, emotional, and physical needs (Clay, Cortina, Harper, Cocco, Drotar, 2004, Duggan, Medway, and Bunke 2004, Hamlet, Gergar, & Shaefer, 2011, Peebles-Wilkins, 2006).

Chapter IV: Conclusion

Children with a chronic illness can find entry into primary school, or moving to secondary school, to be a challenge. To get the most out of their schooling, students with a chronic illness need ongoing and organized support from their families, schools and medical caregivers. A school environment may need physical or social modifications to accommodate a

child with a chronic illness. The problems associated with a student diagnosed with chronic illness cannot be treated in isolation, therefore, training the educational team to know what outcomes to expect can lead to stronger plans appropriately supporting students.

Recommendations

The family and the school need to work together to establish and continue good communication and support. Stakeholders in the child's wellbeing need to understand what is required to care for the child. The family and school also need to be clear on what can, and cannot, be done so that expectations are possible and realistic.

First, the cooperation of medical and school personnel can lead to thoughtful planning that supports the parents and child dealing with the illness, particularly when the child reintegrates into the school setting. This involves more training including pre-service and in-service to help educational personnel understand how to handle the situation.

Second, programs that integrate health and educational needs must begin with a written protocol after diagnosis for each individual child. After the protocol is written the school personnel must create a re-entry plan and subsequent support systems to increase the success of the student. A hospital-school liaison for these students would train the teachers, nurses, or counselors in the proper protocol. Stronger collaboration between healthcare and education systems will ensure that effective plans are developed and implemented for supporting families and students dealing with chronic illness.

In addition, schools can support a student with illness through strengthening pro-social programs that promote healthy relationship-building with peers. Classroom teachers can educate peers about the illness itself, as well as coach students in how to be a friend to the sick child.

Since bullying is a common problem for students with chronic illness, examination and strengthening of school policies related to peer victimization can create a caring environment that will offer psychosocial benefits for students under the stress of treatment for chronic illness.

Finally, the unique issues related to students with chronic illness can be addressed through pre-service and in-service training programs for teachers. Another area needed for research is the possibility for finding Federal funding to support the trainings needed in the school systems to help educators understand the illness. This would include, but not limit to, educational support, training educators, counseling.

Areas for Further Research

The scope of this study addresses the needs of students with chronic illness to help them succeed in school. However, chronic illness creates a complex impact on those who surround the student. For example, siblings are directly affected by a chronically ill family member. Little research exists on how chronic illness in the family affects siblings and their performance in school. Do many of the same issues related to motivation, psychosocial struggles, and academic achievement also exist for brothers and sisters? What are the psychological, emotional, social, and academic needs of siblings in the school setting? How can schools be better prepared to help the siblings of chronically ill students?

Besides impacting family members in the school environment, chronic illness also directly impacts classroom teachers. In particular, elementary teachers in self-contained classrooms face unique challenges in helping students with chronic illness, as they maintain sustained contact with that student throughout the day. While research does indicate that educators have a lack of training in managing a student with chronic illness, there is also a lack

of research on the psychological and emotional impact of educating a chronically ill student. How does having a chronically ill student in the classroom impact a teacher's ability to manage the whole classroom environment? How does such a student influence a teacher's self-efficacy beliefs about his or her job? What kinds of supportive programs are needed to sustain teachers with a student having a chronic condition?

In addition to further research on those impacted by chronic illness in the school setting, research on technological resources could provide benefits for students and their families. What kinds of assistive technology might help students remain engaged with their classroom while they are away due to treatment or recovery? How can technology create a safe interface between the school and healthcare system to maintain shared information that will support chronically ill students?

Conclusion

Educators often assume that outcomes of children with chronic illnesses are solely medical. In reality, students struggle with social competence, behavioral and emotional symptoms, and the need to cope with the complexity of their illness. There is a wide gap between current professional training and the requisite knowledge that educators need in this situation. After successful training educators can help students accomplish a successful inclusion into conventional life experiences in the school.

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