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## Transitioning the Needs of Children with Chronic Illness: Exploring Communication Between Hospitals and School Settings

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TRANSITIONING THE NEEDS OF CHILDREN WITH A CHRONIC ILLNESS:  
EXPLORING COMMUNICATION BETWEEN HOSPITALS AND SCHOOL SETTINGS

A project based upon an independent investigation, submitted in partial fulfillment of the requirement for the degree of Bachelor of Arts in Social Work.

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*Abstract*

Chronic illnesses like cancer, sickle cell anemia, HIV, hemophilia, and metabolic disorders are on the rise. Chronic illness can be defined as an ongoing health condition that requires specialized treatments and may cause limitations in functions, activities or social roles. There are multiple phases that individuals with chronic illness progress through while learning to cope with their condition. Children with chronic illness are likely to spend a great deal of time in doctor's offices and in the hospital. This study hypothesized that there is limited support for and understanding of the needs of children with chronic illness once they leave intensive inpatient hospital settings and reenter the school system. An additional hypothesis focused on the lack of communication between hospital and school providers to support the social, emotional, and physical needs of these children. Using a survey instrument, information was collected from public school social workers, psychologists, and school nurses and from hospital personnel, hospital outreach specialists, social workers, and psychologists. Results of the questionnaire had varied results, but supported the hypothesis that there is a lack of communication between hospitals and schools regarding children with chronic illnesses. Further research should be done to explore the prevalence and needs of children with chronic conditions.

## *Introduction*

### *Problem Formation*

Chronic illness is defined as a health problem that persists over three months and affects normal activities of daily living. These illnesses can require hospitalization, health care, and/or extensive medical care (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997). Chronic health conditions most typically seen in children include; asthma, diabetes, sickle cell anemia, cancer, HIV/AIDS, epilepsy, hemophilia, and other metabolic disorders. Although treatable, these diseases are not curable and therefore require long-term and/or consistent management that can have a psychosocial impact on a child and their family (Kliewer, 1997).

Children with chronic illness are likely to experience frequent visits to the doctor and to the hospital. Many of these children's activities are limited due to extended hospital stays or periods of isolation from peers due to their ailments. In the 1992, the National Health Interview Survey on Child Health, reported that out of the 19,556 responses to a survey administered to children with chronic illness and their families, at least 55% reported feeling "bothered" or hindered by their illness and limited in their ability to be social with other peers (Newacheck & Taylor, 1992). Many children affected by illness are able to reason that they have the illness, but not understand how to cope with the condition. These children sense differences in themselves and their peers. Based on the degree to which the illness hinders normal functioning, there is potential for psychological risk to the child's mental health. Internal resources for the child (family, friends, and community) and external resources and support systems (hospitals, social workers, nurses, etc) can have an enormous impact on a child's ability to cope with their illness (Child Study Center, 2001).

Statistics from 1997 show that about 20% of school-aged children have been diagnosed with a chronic medical illness or disabling physical or mental condition (Kliewer, 1997). That is, over 12 million children who are suffering from a condition and families to match that are dealing with the effects. With the prevalence and severity of childhood chronic illnesses on the rise, it becomes even more important to look at the types of interventions that can be used to teach children and families skills to cope with the chronic ailment (Child Study Center, 2001). Social skills trainings in hospitals and cognitive behavioral strategies are needed to support affected children in order to help with the adjustment and frequent changes in their health. Programs within hospitals and outreach centers should focus on teaching skills that can be recreated both in and outside the hospital environment (Kliewer, 1997). This work with children should be ongoing in order to be replicated at home and during transitional periods. Education about chronic conditions and their impact on children academically and socially should be made available to school systems and other facilities in which children are entering and then re-entering after hospitalizations or treatments (Newacheck & Taylor, 1992).

By tending to and consistently being aware of children's social, emotional and physical needs, there can be huge improvements in children's ability to accept and adjust to their illness while maximizing their quality of life (Child Study Center, 2001). There needs to be a transitioning model that looks at the relationship between the stress of the illness and coping efforts in socialized activity (Child Study Center, 2001).

#### *Problem Justification*

Research has provided evidence that there are multiple phases that individuals with chronic illness progress through while learning to cope with their condition (Fennell, 2009).

Children with chronic illness are likely to spend a great deal of time in doctor's offices and in the hospital. They live in "two worlds"; the world of the hospital and the world of school and community (Child Study Center, 2001). Camps and hospital outreach programs provide a safe "in-house", intervention to children and families. Camps for children with chronic health concerns have been organized to address the physical and psychosocial needs of children with various chronic illnesses, while providing a "normal" as possible camp experience (Kliewer, 1997). Social workers, counselors, and outreach specialists work within these programs to provide children with therapy through activities and individual counseling. The effects of this camp experience in children with chronic illnesses are something to be explored. Not only do they provide support for these children and their families, they have become an outlet and a built in resource to manage the child's illness. However, what happens when the child transitions back into their original environment?

Studies conducted by Geist, Grisa, and Otley, and another conducted by Shiu, have shown that more than half of these children diagnosed with chronic illness are absent from school and social activities more frequently and often for an extended period of time (Geist, Grdisa, & Otley, 2003; Shiu, 2001). The extended absence from their normal lifestyle may interfere with their coping and rehabilitation process. When children and families are effectively able to manage the disease, there are fewer psychosocial and psychological consequences (Geist et al., 2003). There is a need for modeling and creating a program for these children on self-management training and support services, in addition to active follow-up with care providers to support emotional and physical needs of these children (Kliewer, 1997). But where do the programs start, and how are these needs communicated between medical and school communities?

Appropriate medical treatment for their illness is not just a matter of controlling the disease, but also must include attention to the psychological impact of the disease on their lives. Social workers have acted as mediators and supporters in a variety of different fields. When a child's "problems" result from the illness (meaning physical problems), then there is support from doctors, nurses, and specialists at clinics or in hospitals. Psychologically this child may have limited to no control over his or her sickness and how that affects their emotional well being (Child Study Center, 2001). These conditions can create anxieties and fears related to the illness and management, along with an uneasiness of not fully understanding the illness itself, while in the hospital, but then they also have to cope with re-entering school systems and social situations. Little information is given to schools and there is a lack of a general model that is provided to the school system and social networks of the child (Fotland, 2000). Social workers and therapeutic interventions are effective in treating children with these psychological needs, but there still seems to be a gap in the process of transiting these children back into school settings and social activities, in a way that is not evasive to their privacy.

In the past the role of the social worker in treatments for children with chronic illness outside of these supports has been unclear. Direct support and counseling from social workers to children and their families during the process of reintegration from the hospital settings back into the home and school environment would be an effective support to assist families in taking the skills learned in the supportive settings (i.e. hospitals, etc) and applying them to their environment. Children and families need to be taught cognitive-behavioral therapies, social skills trainings, family therapy, and positive reintegration techniques (Child Study Center, 2001) so that as children transition out of the hospital or medical settings, so

too do these coping skills that are being taught. Increased awareness and development of support groups for children and families are needed to further develop these efforts. These efforts should involve ensuring that the child can be as productive as possible and is educated and prepared for independent adult living. Hospital-to-home and school transitions should emphasize home and family involvement that includes self-management strategies, flexible school days, and increasing understanding of the illness (Kliewer, 1997). With the consistent help, communication and treatment from social workers, the child's illness may be effectively integrated into his or her family and school life (Kliewer, 1997).

### *Literature Review*

#### *Prevalence of and Subsequent Medical Care for Children with Chronic Illness*

There are multiple definitions of chronic illness but for the purpose of this study, chronic illness will be defined as an ongoing health condition that requires specialized treatments and may cause limitations in functions, activities or social roles (Drotar, Witherspoon, Zebracki, & Peterson, 2006). Chronic illnesses like cancer, sickle cell anemia, HIV, hemophilia, and metabolic disorders, are on the rise. The prevalence rate of children with a chronic illness is increasing, even though medical treatments for these conditions are improving. In 2000, a survey found that 18% of children in the U.S have a condition that requires long term care and hospitalization (Drotar, et al., 2006). The impact of chronic illness in children has a complex bearing. Children with these conditions endure and experience painful procedures associated with their diagnosis and have to develop different ways to deal with the acute and chronic pain that comes with the illness.

Pediatric cancer includes a range of conditions such as leukemias, lymphomas and tumors. In a 1996 study by Ross, Severson, Pollack and Robinson, it was estimated that 1 in



every 330 children in the United States is diagnosed with cancer (Drotar et al., 2006). It is the leading cause of death for children in America under the age of 15. On average children diagnosed with cancer, are treated with a month of intense chemotherapy followed by at least a year of radiation treatment and other therapies that require frequent doctor's visits and possible hospitalization (Drotar, et.al, 2006). The radiation and treatment interventions for cancer have multiple side effects, such as hair loss, post treatment nausea, and fatigue. These treatments limit a child's ability to participate in school and social activities and may cause cognitive impairments. The CNS effects of treatment may slow processing, and precipitate memory loss and motor difficulties (Butler & Mulhern, 2005, in press Drotar et al., 2006).

After five years of being cancer free, children with a cancer diagnosis are considered "cured". However they continue to be at higher risk for growth problems, obesity, cardiac, pulmonary, ocular, gastrointestinal, dental problems and impairments (Drotar, et al., 2006). The later effects of certain cancers as well as the treatment of these cancers have been identified as contributing to health problems in almost every organ system (Hayman, Mahon, & Turner, 2002). In addition these children are susceptible to developmental and cognitive delays. Given the trauma and the anxiety that the illness plays on the child, there are ongoing concerns about the future development of the child, physically, socially and emotionally. Hospitals use behavioral coping strategies to manage the pain and trauma induced by treatments. These frequent hospitalizations result in time away from school in addition to the painful procedures, physical changes, and may lead to psychological responses (Hayman et al., 2002).

In 1989, Mulhern observed that children, who had remained in remission after a year of therapy, were more likely to report incidences of increased behavioral problems and

deficiencies in social competence as compared to the norms of the Child Behavior Checklist. Then in 1994, Haase and Rostad, designed a study of individual interviews and reported on their finding about the effects of cancer treatments for children in remission. They found these children had; reoccurring fears about their cancer returning, desires to live normal lives, and a need to mend relationships with peers. Even more recently, in 2000, Mackie and his fellow researchers reported that in a sample of 102 cancer survivors of childhood leukemia, found that their sample showed greater difficulties with friendships, relationships, and day-to-day functioning (Hayman et al., 2002).

Unlike childhood cancer, sickle cell disease, caused a mutation in the hemoglobin, is a life-long blood disorder. Children with sickle cell disease or SCD may experience anemia, chronic or acute pain, frequent needs to urinate, malnutrition, iron and protein deficiencies, and strokes (Bonner et al., 1999). Skeletal complications, impaired spleen development, and pulmonary events cause frequent hospitalization. Children with a diagnosis of SCD experience multiple “pain episodes” that can last one to three or more days (Lemanek et al., 2003), leading to hospitalizations or intensive home based treatments. Life expectancy is shortened, with studies reporting an average life expectancy of 42 and 48 years for males and females, respectively (Platt, Brambilla D, & Rosse W, 1994).

Daily penicillin prophylaxis has been used to prevent sickling of blood cells which causes the painful crisis. Cases of sickling can be triggered by stress, dehydration, cold temperatures, and fatigue. All of which are may occur in the everyday life of a child. Cohen, Branch, McKie and Adams (1997) demonstrated that SCD may weaken verbal and intellectual functioning in the left hemisphere of a child’s brain. This illness can cause neurocognitive functioning that may affect school and social performance and functioning.

There is a need for ongoing planning and intervention for children with SCD due to the nature and the frequency of the illness. There is a high prevalence of SCD in children who are of an African American decent (Cohen, Branch, McKie, & Adams, 1997).

Although these children can typically function and participate in physical activities, they need to be careful not to overexert themselves (Wishnietsky & Wishnietsky, 1996). Children with SCD need more recovery time during activities, especially because painful episodes often come on gradually. Oral medications can be given at home or in school for mild episodes. A major medical concern for children with SCD is infections. If exposed to illness or if these children present with symptoms of a viruses or the flu, they may be admitted to the hospital for antibiotics (Wishnietsky & Wishnietsky, 1996). This disorder does not present with physical defects, but often leads children to feel isolated because of the lack of knowledge people have about the condition (Wishnietsky & Wishnietsky, 1996).

As with sickle cell, children with hemophilia may not exhibit visual signs of the disease. Hemophilia is a rare bleeding disorder that prevents the blood from clotting properly. It is estimated that 17,000 people in the United States have hemophilia (Manco-Johnson, Riske, & Kasper, 2003). About 1 in every 5,000 boys is born with this condition. It is a chronic condition with no cure and can be managed by clotting factor replacement therapy.

Toddlers and teenagers struggle the most with hemophilia, because even though these children can participate in normal activities, contact sports and activities need to be eliminated to prevent serious injury and internal bleeding. Children with hemophilia can bleed easily when injured and have bleeding episodes. When a child loses a lot of blood with a bleeding episode he or she may need a transfusion or surgery. Although this condition can

be managed in everyday life, these children are limited in activities and sports that promote social relationships (Manco-Johnson et al., 2003). Over time, this can lead to arthritis with decreased function and chronic pain in the injured joints.

Metabolic disorders are a type of chronic illness that has a range of types and intensities. One type of metabolic disease is phenylketonuria or PKU. A child with PKU has a deficiency a certain type of enzyme that breaks down an essential amino acid causing the essential amino acid to build up in the body, and cause a variety of problems. For the most severe form of PKU, dietary treatment involves elimination of all "high-protein" foods, since all protein contains phenylalanine (Dawson, 2003). Any common illness or infection can cause or precipitate an episode of vomiting, diarrhea, irritability, sleepiness, unusual breathing, staggering, hallucinations, and slurred speech. Special diets are supplemented with low-protein foods and weighed or measured amounts of fruits, vegetables, and some grain products. These types of foods contain lower amounts of protein, but provide the necessary amount of essential amino acid(s) based on the patient's specific presentation of the disease (Dawson, 2003).

Between 10,000 and 20,000 children in the United States are infected by HIV, a virus that leads to AIDS. AIDS has become not only a health issue but also a social issue because of the means of transmission (Drotar et al., 2006). AIDS is the failure of the body's immune system making the body unable to fight off fatal diseases. HIV, the virus that causes AIDS is different from other types of chronic illness in the fact that it causes a deterioration of the body's built in protection. There is a lapse of time between when a person acquires the disease and when the virus begins to produce harmful antibodies. Infections and bacterial viruses can even cause a child to develop Kaposi's sarcoma which is a type of cancer.

Childhood AIDS and HIV differs from the disease in adults. Young children with HIV become ill more rapidly than adults (Wishnietsky & Wishnietsky, 1996).

There have been many advances in the medical management of children with HIV. Treatments include identification of HIV, antiretroviral treatment, prophylaxis, treatment of active infections and supportive care. There are numerous problems that limit children's access to medical treatment including the high cost of antiretroviral drugs and the lack of trained healthcare workers available to treat children. Children living with HIV are more susceptible to childhood illnesses, such as mumps and chickenpox (Hayman, et al, 2002). They must be more aware in class rooms and with social interactions to prevent compromising their health.

All these conditions may have issues of constant and chronic pain associated with the illness. Constant pain affects and disrupts the child's body from functioning normally. This pain is insidious and may be triggered by typical activities. Not only are these children frequently hospitalized, but they are forced into maturing at a different rate than their peers (Hayman, et al., 2002). These children are learning their limits and trying to prevent further complications while dealing with the stressors and obstacles of their environments.

#### *Effects of childhood chronic illness on school attendance, academic performance and social relationships*

Management of a chronic illness requires a regime in a child's daily routine to prevent symptoms and consequences of the illness. Within these routines, these children are making time for tests, hospital visits, therapy and medical visits. Children may have periods of "good health" alternating with periods of illness from the disease. Even when children

and families have a daily routine or regimen to control the condition, they still may not be able to achieve their expected outcomes (Wishnietsky & Wishnietsky, 1996).

Changes caused by chronic illness can be permanent. Having an illness affects a child's relationships, emotions, self-esteem, security, and independence, as these children mature, they are introduced to concerns in school and at home. The reaction to body image, self-esteem and "peer acceptance" elicits a different type of internal reaction (Drotar, 2006; Haymon et al., 2002; Wishnietsky & Wishnietsky, 1996). These children can experience insecurities because of the evident differences from their peers at school and at home.

School aged children with chronic illness are at a higher risk of experiencing problems with school and social functioning. These issues may range from frequent absences from school to learning impairments. On average 10-15% of children with chronic illness attend class regularly but may need different accommodations both in and out of the classroom to maintain their success (Drotar et al., 2006).

The nature of treatment for cancer in particular, places many demands on children and their families. Treatments like chemotherapy and radiation often prevent children from attending classes or social activities. It is common to see learning problems or cognitive implications in children with certain cancers including; drops in IQ sometimes by 10-20 points, problems with memory retention, low academic scores, slower brain development and behavior problems (National Cancer Institute, 2009). Besides the physical and medical effects of cancer, these other implications play a significant role in the effective reintegration of the child back into the classroom. Information found in an older study indicate children with leukemia report missing up to 10-20 weeks of school in one year, and as a result, many children repeat grades (Mulhern et al., 1989).

Children in remission still need to deal with issues like losses or compromises because of their illness, living in fear that the cancer may return, and developing relationships with peers after long absences. In addition, psychological issues such as depression, anxiety, lack of interest and poor self esteem can occur (Drotar, et al., 2006; Child Study Center, 2001; Hayman, et al., 2002; & Wishnietsky & Wishnietsky, 1996).

School for children is a place of learning but is a place for social interaction and developing friendships. The ability of the child to be successful in these interactions can be thwarted by the change in physical appearance that often occurs in children with chronic illness. Studies of youths that have undergone cancer treatment conclude that "In general, a poor body image is associated with self-rankings of academic, social, and psychological impairment, low self-esteem, and symptoms of depression" (McDougal, 1997). At a time when most children are able to thrive socially and emotionally, children with cancer and other chronic conditions are left with intense frustration, inhibited and withdrawn behavior; fear of trying new things; low emotional expressiveness. In a study by, Varni, Katz, Colegrove and Dolgin (1994) they provide a reason for these psychological difficulties; "the chronic strains of childhood cancer, such as treatment-related pain; nausea and vomiting; visible side effects such as hair loss, weight gain or loss, and physical disfigurement; and repeated absences from school and peers, interact to negatively impact social and psychological adjustment"(p. 20).

Similar to children with cancer, sickle cell or SCD in children can give rise to psychological issues. Physically children who have SCD may look younger than their peers because of the delay of puberty, thus there is that same issue of body image and physical appearance in the school and home environments (Wishnietsky & Wishnietsky, 1996).

Socially and emotionally this physical difference is demanding on a child who is already going through a process of integrating an illness into their lifestyle and now has to explain physical differences.

Extended absence from school is another big issue that can result from chronic illnesses like SCD. For medical reasons, children may be absent up to 50 days during the school year (Wishnietsky & Wishnietsky, 1996). Prolonged absences contribute to a sense of learned helplessness which interferes with the normalizing and socializing process.

The illness places limitations on the amount of physical activity a child can partake in. These children want to be “normal” and participate in many of the same activities as peers, but there are concerns that arise for children who have to “get out of...” something because of their illness. Peers may not be supportive as most children with SCD do not have physical manifestations of illness (Wishnietsky & Wishnietsky, 1996).

Other metabolic disorders require children to be on specialized diets that restrict certain foods that are common in everyday meals. Stopping the diet can result in a variety of serious problems, including deterioration in IQ, learning disabilities, behavioral problems such as hyperactivity and irritability, neurological problems and personality disorders including schizophrenia, panic attacks, and agoraphobia. It is therefore strongly encouraged for PKU patients to follow their prescribed diet for life (Dawson, 2003).

Diets and specialized treatment plans are used to keep children out of the hospital, but may be hard to effectively maintain in everyday life. In study cited by Dawson (2003), teachers reported that on average academic performance of the PKU patients was associated with recent level of dietary control, which suggests that it might be improved by stricter adherence to the diet. In general, these studies have found that despite early treatment with a



phenylalanine (Phe)-restricted diet, PKU patients demonstrate more behavioral and school problems than do healthy controls. The behavior problems include “internalizing symptoms” or solitary, unresponsive, anxious, depressed mood (Dawson, 2003). With respect to school achievement, studies have shown that patients with early treated PKU more often repeat classes or need special tutoring

Different constraints and social pressures with the need for independence can interfere with dietary control. Like children who are suffering from cancer and SCD, these children are going through biological and physical changes and these factors play a role on their psychological well being in and out of a classroom (Wishnietsky & Wishnietsky, 1996). These children need support from families and school environments with flexibility in meals and provisions for alternatives for meals.

Hemophilia care is another example the effects of chronic illness outside of medical care. The management of hemophilia lies with the patient. Children with hemophilia have often been viewed at greater risk for altered self-esteem than their healthy counterparts. There is simply no way to guarantee a child won't ever get hurt. Excluding them on a regular basis can unintentionally isolate them, contributing to poor self-image and poor acceptance of their disease and treatment (Manco-Johnson et al., 2003). Physical or functional limitations can make young children feel shy and embarrassed or cause them to be teased by others.

In many families and communities the environment for healthy growth and well-being has been devastated by HIV/AIDS. Due to the stigma of HIV and AIDS and lack of knowledge that children and families have about the diseases, kids can develop feelings of insecurity, fear, loneliness, grief or despair (Drotar et al., 2006). It limits the possibility of a

successful childhood which, in turn, affects their future as adults. During the years of physical growth in which a child matures towards adulthood, the child is also developing psychologically and in ways that define intellectual, social, spiritual and emotional characteristics. Typical physical and emotional well being and social and intellectual development can be permanently limited for a child living with HIV (Hayman et al., 2003).

Other concerns reported by families dealing with HIV/AIDS involve interacting with the medical environment and addressing medical concerns due to stigmas and finances. Families and children are coping with hospitalizations, clinic visits, and important medical decisions. Caregivers are often required to manage their children's medical condition as well as their own, and social relationships of children in and out of school are delayed. There is a silent aspect of HIV/AIDS due to the stigma and isolation that accompanies it (Drotar et al., 2006). Despite improvements in understanding of HIV/AIDS, those who are infected continue to face possible fear, rejection, and prejudice if and when their diagnosis becomes known. Children with HIV/AIDS may exhibit a number of behavioral and psychosocial difficulties including hyperactivity, attention deficits, social withdrawal, and depression. It is oftentimes difficult to ascertain whether symptoms of these disorders are behavioral/emotional or neurological in nature (Drotar et al., 2006).

Chronically ill children tend to be more submissive and less socially outgoing than healthy children. Further, kids who live with pain and physical restrictions may be more likely to have problems relating to their peers. "When kids are out of school for long periods, they miss both cognitive and social learning," says Nina Bass, MD, a behavioral medicine specialist and assistant clinical professor of psychiatry at Emory University School of

Medicine in Atlanta. "And no matter how hard they try, parents can't give kids the same social experience they get at school" (Croft, 200).

### *Camps and outreach programs*

There are camps and affiliated hospital outreach programs that provide support for children and their families while they are adjusting to and receiving treatment for their illness. They are useful as support to try and improve the lives of children and families who are suffering from serious and chronic illnesses. These camps are built on the foundation of safety, respect and love of one another. Using a child-centered program model also known as intentional programming and therapeutic recreation, these camps have had a profound and positive impact on children's lives and their recovery. "Therapeutic Recreation and Intentional Programming are designed to improve children's functioning abilities, facilitate their independence, and remediate the psychosocial effects of illness. By teaching recreational skills and attitudes that promote health and growth, these programs help children regain their confidence that can be used throughout their lives" (Hole in the Wall Gang Camp, 2009).

Some camps focus in on the needs of children who have a specific chronic illness, where as others have a more "general" population that incorporates children with all different diagnoses. This is a way for children to meet others who may be experiencing issues similar to their own. In these environments, everyone is the same, and that eliminates worry about differences. These camps have designed programs and activities to support families and siblings as well.

Several hospitals have begun to develop Hospital Outreach teams (HOP), which brings the spirit and mission of camp to children who are seriously ill in the hospital. In

2008, Association HOP programs implemented programs that served the needs of more than 17,500 children and families. During the in-hospital camp sessions, children participate in activities designed to promote self-confidence. “The time spent with the child is designed to help improve their quality of life, reduce anxiety and temporarily transport them to a camp environment where fun and laughter are at the forefront” (Hole in the Wall Gang Camp, 2009).

These camps and outreach programs are a major support and relief for children and families, but after camps and hospital outreach ends, programs need to be implemented to help build confidence and support children and their families in understanding and managing their illness are needed.

#### *Transitioning back into school and home*

Chronic illness does have an impact on school and social development. On estimate, 45% of children with a chronic illness reported falling behind in their school work, which lead to negative feelings about school and their peers (Wishnietsky & Wishnietsky, 1996). These students are at a greater risk of social isolation because of their peers’ misunderstanding of the disease.

Returning to school is a difficult transition for children with chronic illness. There are more positive effects of the collaborative work with schools, families and hospitals in a child’s reintegration back to home and school environments (Wishnietsky & Wishnietsky, 1996). This re-entrance can be facilitated by a multi disciplinary support team that could include personnel from the hospital, outpatient services and school. It is important that these children are entering a supportive environment where teachers and staff have an understanding of their unique needs.

The appropriate education of school staff can be crucial to enabling a child to thrive in school and social situations. Children with chronic illness, as Wishnietsky and Wishnietsky (1996) state, are “not the disease.” The way children are referenced in and out of class is important. This illness is part of the child’s life and the child is a part of the class, therefore when appropriate, these illnesses should be incorporated and shared with children in the environment.

There is a paucity of research on hospital to school transitional programs for students with chronic illness. Little is supported about whether there is improvement in student outcomes when students with chronic illness have social emotional support or are provided with transitional support programs or when teachers and staff are educated about their needs in school.

#### *Opposing Points*

In both the classroom, and home environment there have not been consistent findings on interventions that support children with chronic illness. Nor is there evidence that supports a need for psychological interventions, due to an inability to identify that they produce a positive outcome (Glasgow, McKay, Piette, & Reynolds, 2001). Children with chronic illnesses encompass a multitude of diagnoses and stages of illness and therefore it is difficult to produce evidence that psychological interventions and school transition programs are useful for the child and family.

The first point of debate is whether children with chronic illness require support as they reintegrate into family, school and social life. Perhaps the percentage of children in question does not necessitate provision of resources to support their needs (Sartain, Clarke & Heyman, 2000).

Much of the work that psychological treatments are based on is correlated to the needs and the prevalence of children in classrooms and in the community that have a chronic illness. The actual number of cases of children with chronic illness and its prevalence varies and is not well known. Research has been done based on the National Health Interview Survey, which estimates the prevalence of chronic conditions. It suggests that 6.5% of American children have a chronic condition that affects their physical health while only looking at specific types of chronic illness and thus there is no accurate measurement of prevalence of chronic illness (Hoffman, Rice & Sung, 1996). A child's diagnosis cannot be what predicts the course of chronic illness and its effects. It is also difficult to look at children with chronic illness and treat them as a homogeneous group (Sartain et.al, 2000). Specific diagnoses cannot predict the need for health or education services and this makes transition programs for schools to implement quite difficult (Thies, 1999).

Services are typically created and provided to address the needs of a specific population. There are no facts and figures that support a need for treatment and transition treatment for children with chronic illness. The paucity of research that has been done with populations of children with chronic illness is limited by the number of participants that are available to be in the study (Newacheck, McManus, Fox, Hung, & Halfon, 2000).

The second point of debate is that the needs of these children may be best served in the hospital setting. Many studies are also based upon a certain specific illnesses, such as cancer. Typically children may be involved with hospitals that specialize in medical treatment of their illness. Research may follow cases from a particular agency or hospital and those children may be in and out too sporadically being able to evaluate (Thompson, & Gustafson, 1996). These children often come from a distance and are most likely not in a

local area. In fact children treated by one team of medical providers may be from many different school districts, and therefore there is a lower chance of building communication between schools and hospitals or medical providers.

Because of this, support programs may be most useful as a part of the medical center. In such situations, in-hospital specialists would coordinate programs that are in hospitals and medical centers. The argument to support this model is that it would foster relationships amongst children who are struggling with similar issues and would be more likely to understand the situations (Thies, 1999).

Models of intervention, for example hospital outreach programs, incorporate therapists interacting extensively with child participants. Since these interventions and treatments are based on relatively small number of pediatric intervention studies, “the use of these criteria as a sole basis for making judgments about the evidential status of an intervention has been criticized as insufficiently reflecting the dearth of evidence that research findings can be applied to real clinical settings and to ordinary clients” (Chambless & Ollendick, 2001, pg. 690).

Small sample sizes limit the level to which researchers are able to generalize their findings. Katz (1992) researched psychological interventions for children with chronic illness using a control group, evidence of measurement validity and reliability, and pre-/post evaluation procedures. Katz found the children who did not receive treatment demonstrated behavior problems, and were less likely to have a positive; social competency, self-concept, acceptance by peers, and teacher knowledge. This comprehensive research produced some results however because of the sample size, the research could not be generalized to a greater

population, nor would this research be able to be replicated and produce similar results with another sample of the population (Katz, 1992).

There is not only a lack of research to support that these interventions work, but there is also little evidence that there is a greater need for transition services from hospitals to school; and psychological interventions (Miller & Rollnick, 2002). The data that is presented infers that children and families may have been receptive to the interventions, but that they were not necessary. Without identifying a need there is a further issue of how to go about implementing any type of reintegration or transition program for children. Some programs are initiated with outside grant dollars or funding but would not be able to become self-sustaining or would limit the families eligible for service due to financial constraints (Newacheck, McManus, Fox, Hung, & Halfon, 2000).

Schools have barriers that make some individual accommodations for the child based on social and emotional needs difficult to implement. Some interventions may create barriers that hinder the relationships between peers in classrooms. There is also the potential that a label may be given to the child who is sick (Glasgow et. al, 2001). They become “the disease” instead of the child. It would be more effective to have hospital based support programs for children so that they are relating to peers like themselves.

Funding issues may limit the implementation of this coordination for reintegration programs for children. While these models can be created in theory, implementing them can be difficult (Hoffman, Rice, & Sung, 1996). Monies are necessary to create programs, hire appropriate personnel and train existing personnel. The nation’s success in building high-quality, integrated systems of care at the community level have been fairly limited. Some communities have been able to get a few agencies to work together, but it is not complete and



there are many gaps in the system. While government can assist with funding, only a local community can establish the authority, power, and legitimacy of an integrated service model. Costs for treatments outside the hospital may not qualify for reimbursement (Hoffman et al., 1996).

There are many barriers to psychological interventions for children that have chronic illnesses. These children do not present a need for support services. Hospitals and medical teams already provide a comprehensive program to transition children. These programs and interventions should be implemented in hospitals and not school systems (Prevatt, Heffer, & Lowe, 2000). In addition the costs of these programs are too expensive and do not do a good job of interacting and interfacing between different agencies like the hospital, private practice, home and school settings.

### *Hypothesis*

It is hypothesized that upon discharge from a hospital setting, children with chronic illness face multiple setbacks (both emotionally and physically) that create obstacles in their transition back into their school system and that these social and emotional needs are not being communicated between these two systems. There is limited support for and understanding of the needs of children with chronic illness once they leave intensive inpatient hospital settings and reenter the school system. In addition it is hypothesized due in part to the lack of communication between hospitals and school systems during the child's hospitalizations and transition, that there are continuous social and emotional needs of these children that are not being addressed when they return to the classroom settings. With better communication between hospitals and school systems, information about needed supports

and emotional interventions employed within the hospital could be considered to support the child to facilitate successful transition back into the classroom and community.

### *Methodology*

#### *Sample*

This is an exploratory study, using a survey to examine the prevalence and needs of children with chronic illnesses in schools and hospitals. This research study explores the existing relationship between the two systems to fully understand the transition process for children with a chronic illness. This descriptive study will summarize a set of observations taken from the data collected in the survey. It is a “shallow” study that will take a snapshot look at the prevalence and needs of children with a chronic illness in school systems, as well as the relationship between schools and hospitals.

#### *Participants*

A survey was sent to both public schools and hospitals in three states in the New England area, which were randomly selected and sent either an email or mailed a copy of a survey. Each of these New England states has a leading medical center that specializes in the care of children with chronic illnesses like cancer, sickle cell, metabolic disorders, HIV/AIDS, and hemophilia. A proposed sample of 3 public schools in each of the aforementioned states was sent with a request for social workers, school psychologists, and/or school nurses to complete separate surveys for a total of sample 14 school questionnaires. Questions on the survey ask for the demographics of the schools and the prevalence rate of childhood chronic illness (such as the aforementioned conditions above) within the school, either presently or in the past. A corresponding questionnaire was sent to 10 hospital personnel, some were social workers, while others work in as outpatient hospital

settings as psychiatrists, and hospital Outreach Specialists. The survey instrument posed questions about the support offered to the child with chronic illness while in the hospital. And, just as in the school survey, questions were included regarding whether they have any communication with the child's school.

Recruitment and selection of the subjects was done by canvassing the school social workers, psychologists and nurses along with hospital psychiatrists and Outreach Specialists in the three states. Snowball sampling was used by giving surveys to classmates who are education majors to give to school personnel, and by asking hospital workers to distribute surveys to colleagues. Participants were given the option to send the survey back in a stamped addressed envelope or complete through an online survey. Participants and their institutions are to be left anonymous and no personal information will be disclosed in the findings. In addition subjects were provided with an information sheet that describes the purpose of this study and allows him or her to give informed consent for participation. The consent information explains that at any time participants are free to discontinue their involvement in the study (See Appendix A).

### *Data Gathering*

A questionnaire/ survey was used to collect data on demographics, prevalence, and programs for children with chronic illness. Subsequent questions addressed whether the schools had any support groups or programs for children with chronic conditions to help with their social, emotional, physical and educational needs (See Appendix B). A key question asked of the schools participants was whether there was any communication with hospital or medical personnel about a child's medical condition or communication with a hospital social worker/psychologists/etc. The ultimate question to the hospital social worker would be; what

does the follow-up or transition process look like for the child when they leave but are still in need of medical and emotional support? This study identified hospital outreach programs to explore if these programs provide a plan for helping a child transition back into the community (See Appendix C).

### *Data Analysis*

Once the data was collected from the survey, the information was compiled by focusing on reoccurring themes, to examine whether the data supported the hypothesis of the study. The questions in the section that deal with the public school systems corresponds and complements the questions for the hospitals. The responses to these corresponding questions will be explored to see if the answers show any form of communication between the two systems. From these results, there may be hope for new programs to be implemented for these children within the settings.

Data collection focused on the correlation and patterns in the responses and also on the general overall patterns and themes of social, emotional, and educational support for children with a chronic illness. The data collected from the surveys will be analyzed and compiled to indicate general consensus of the need for or continued support of programs for children with chronic conditions through the supports of hospital and school settings.

## *Results*

### *Demographics of participants*

Out of the 24 participants surveyed from various public school and three large hospitals in New England; 14 responses were from school personnel and the other 10 were from hospital specialists. Of the 14 school responses; four were from school nurses, six from school social workers (L.C.S.W.) and the other four from school psychologists. The schools

surveyed were public elementary and middle schools, and the responses were collected from seven different schools in the New England area. Out of the 10 hospital specialists surveyed, four were hospital outreach specialists, three were social workers (working in both in and outpatient hospital programs) and three were psychologists (in both inpatient and outpatient programs).

*School demographics and personnel makeup*

There was a wide range of school locations and the student bodies had varying socio-economic stratification and ethnic breakdowns. Of the seven schools, three were in urban districts, and the other four schools were located in suburban districts. The average number of students attending these schools was between 300-500 students; in the urban districts the students were predominantly African American and Hispanic and in the suburban school systems the students were mostly Caucasian, but still had a significant African American and Hispanic population.

Participants were asked about the support personnel (i.e. school social workers, psychologists, and nurses) in the schools and about the amount to which these supports were available to students. All seven reported to have both a school nurse and either a school social worker or psychologist available to the students. The extent to which they were available ranged from office hours three times a week to being present at the school daily. The school nurse at one of the schools “floated” between two different schools in the same district, but was available to the students either by phone or during regular school hours, with an office in both locations. The other three were available to students throughout the school day. Two of the school social workers were split between two or more schools within their district, but were at each school at least twice a week and on call if emergencies arise. The

other four were on staff at only one school, and were at the school during regular and/or after school hours at least four days a week. The school psychologists mirrored the permanent school social workers.

Based on the responses to the survey, participants suggested that the school social workers and school psychologists are the key contact people that deal with children's social and emotional issues outside of the classroom. All 14 participants currently or in the past had children in their school systems that endured a chronic illness, such as cancer, sickle cell disease, HIV/AIDs, hemophilia or any type of metabolic disorders including diabetes.

Of the responses from nurses, all reported to have worked with children who are dealing with diabetes or sickle cell disease. One reported working with children affected by Phenylketonuria (PKU), which is another type of metabolic diseases. Three out of the four have worked with children who have been diagnosed with hemophilia or cancer. One reported working with children who was HIV positive.

The ten school social workers and psychologists varied in the degrees in which they worked with children with a chronic illness. None claimed to provide services related to social or emotional needs for children with hemophilia and metabolic disorders. Half of these support figures stated they have been a part of meetings about school attendance and educational services for children with sickle cell disease. Another two have worked with families around school attendance and educational services for children with metabolic disorders. Seven out of the ten support personnel have worked with or been a part of services for children diagnosed with cancer and two worked with children who were HIV positive.

Six participants responded that there was not a great deal of prevalence of work with the student population around social and emotional needs due to a chronic condition. Their

cases of students with chronic conditions varied and were inconsistent year to year. Two school social workers did report having to provide grief counseling to the student population after the death of a peer from cancer. Also four participants stressed that there are many academic modifications and services for children when they have been absent from school due to illness, but although social and emotional support is offered they are usually not called upon to address those needs of the child.

*Prevalence of and services for chronic conditions in schools*

Diabetes mellitus was the most common illness reported in the schools. Most students affected by diabetes were reported as Caucasian, and from the suburban schools. These students were visiting with the school nurses depending on their needs and help managing the condition. According to two school social workers, they have educators, nurses, and other school figures that occasionally meet with families to develop plans to support the child. None of the school participants reported social or emotional services (like counseling) for children with diabetes. However all of the nurses did report that they had programs or individual conferences with families dealing with managing the disease at school. Three nurses report that if a child is hospitalized from effects of their diabetes, most hospitalizations do not last for a prolonged period of time.

The second most common illness that the school nurses reported in children was sickle cell disease. These nurses reported that all of the students they treated or see for SCD were African American. They reported seeing children in school during or after the child experienced a sickle cell crisis, and were typically treated in school with medication. However depending on the child, the amount or severity of the episodes varied. School social workers reported that they had been a part of an interdisciplinary team to discuss the child's

educational plan. Unless the child experienced a prolonged absence, social workers were not involved in services for social and emotional needs of children with SCD. Two nurses reported that parents or physicians would give the school information about the individual needs of the child.

Three school nurses and six school social workers and psychologists have worked with children that were diagnosed with cancer. Although there were minimal visits to the school nurses, while the children were in school, they kept in contact with the child and would take on the responsibility of contacting the hospitals if a child felt ill. The school nurses and four of social workers and psychologists reported having attended an interdisciplinary meeting for a child newly diagnosed with cancer to discuss their educational needs and prolonged absences. All nine reported that individual academic modifications or accommodations were made for these students. Typically academic services outside of school were on an individual basis and provided for the most part by teachers or educators.

The three school nurses reported that they would sometimes receive contact from the student's hospital provider. One social worker reported that because each child is unique in what they need for services, she has acted as support for the child after they have returned to school. All of the school participants answered yes to the schools having an individual plan for the child to allow for medical treatments or extended absences from school due to their chronic illness. Each reported that the schools have plans for the children that are developed to fit their unique needs and they varied depending on severity of the child and their condition.

Although there are protocols according to one school social worker, she stated that the school did not have a "standardized approach" to transition children back to the school



community, and that it was mostly if anything a meeting with the family to discuss a plan for the child depending on their needs. Six participants answered that there should be more supports or interventions within the school system for children with chronic illnesses. Eleven reported that programs for children with chronic illness would be helpful or successful in helping to transition from hospitals to school settings. However only three answered that they thought programs for children with chronic illnesses are necessary in schools.

When answering if a child with a chronic illness is out for an extended period or hospitalized, “Do you receive any contact from the student’s hospital or primary care provider” nine answered “Sometimes”, two answered “Never” and three answered “Always”. Ten participants answered “No” to the question regarding if there was a contact person/liaison that works and communicated with both the school and hospital setting.

There were various responses to the question, “Do you think having a chronic illness affects a child socially? Academically?” Most participants answered to the extent that long absences from school hurt the child both academically and socially. However one participant said “I think it really depends on which condition they have been diagnosed with. If a child has cancer they are more likely to have more obstacles and challenges academically and socially than a child who has diabetes.” One nurse said “I think that children, especially children dealing with SCD, have a lot of emotional needs that go under the radar because they are hidden by the stressors of everyday life. I think because of the effects SCD, or HIV has on a child’s appearance they are often teased, which causes social obstacles.” Another said,

“Programs are a great idea in our heads, children would benefit from these interventions because I do believe they are affected socially and emotionally, however there is not enough of a need in schools. I typically work with children who are abused or work often with agencies about a child’s behaviors, I personally do not

see an overwhelming presence of children with general needs emotionally in school due to a chronic illness.”

One other response reported:

“I think that a prolonged absence for any child from school will have an impact on their social relationships with others... I see it in individual cases of children affected by cancer and they wonder; How do you explain the hair loss/physical appearances that are different? Their inability to catch up due to another medical procedure?... Many times these children are held back, and that is probably the biggest blow to a child’s social status!”

### *Hospital Demographics*

Three major hospitals in New England were surveyed. All participants reported working full-time (40 plus hours) a week, and have treated and or worked with children with chronic illnesses. In each of the hospital there are programs that address the social and emotional needs of patients and their families. These hospitals provide outpatient services ranging from support groups to individualized outpatient counseling for patients, families, and/or siblings.

The four Hospital Outreach Specialists, have a degree in Child Development or Child Life. The Outreach Specialists work on different pediatric floors throughout the hospitals with multiple children each day. They see hospitalized children diagnosed with cancer, sickle cell disease, HIV/AIDs, metabolic disorders and children with severe hemophilia. Their jobs within the hospital are to visit with children and families and run the playrooms and various activities for the children to participate in. They are present four times a week but may not be able to visit with children every day and typically they see a child once a week.

The three social workers, each from a different hospital have their MSW. Two of them work on different floors within the hospital for children and families dealing with a chronic illness, and have been hospitalized. The other social worker works with other

psychologists in outpatient services for children and families dealing specifically with sickle cell disease. These social workers can act as case managers for children, but are typically available on a weekly basis/rotating basis for children and families or in a time of crisis.

Of the three psychologists, two provide outpatient services to children and families and counseling in addition for children with sickle cell disease, HIV and cancer. They are in the hospital six days a week and have varying hours. They see patients when needed or requested. The other psychologist works directly with children that have cancer and has been published for her research in the social, emotional, and cognitive effects cancer has on children. She works everyday and has monthly check-ins with clients to maintain a connection.

All of the participants said that there are interventions and supports available to children in these primary care settings. Of those who participated in the survey, five commented that they work five or six days a week and that if they were unavailable to the children, someone else is covering their position.

#### *Programs and services for children in the hospital settings*

Out of the ten responses from hospital personnel, eight answered, “Yes” to the question; “Do you have programs in place that address the social and emotional needs of children and their families in the hospital?” When asked if there are support groups for children with chronic illness or any individual/outpatient services, nine participants each went into detail about their hospital and even their specific programs. One outpatient service provides children with sickle cell anemia and their families’ education on the community and healthcare providers to decrease the number of hospitalizations and emergency rooms visits for children while providing coping strategies on how to deal with pain during a sickle crisis.

Another outpatient service provided by one of the hospitals according to a hospital social worker was a clinic devoted to survivors of childhood cancer, in which it provides both care and support to patients. While in this facility children can receive services such as child life, clown visitations, music and massage therapies according to one of the Hospital Outreach participants; “These services are aimed to help children to cope with illness and treatment”. A social worker spoke of her partnership with a specialized hospital for children with cancer and their follow-up care plan with families that included visits on a “regular” basis with the family and child. There is also a psychiatric inpatient service that has emotional problems that coincide with chronic conditions such as diabetes.

Five out of the ten participants said that there was no contact person who communicates with the school systems directly, and three left the question empty because they were unsure if there was or not (as they noted). In addition five of the participants reported that children are typically referred to outside providers for needed support after discharge. Educational services for patients were reported as an individual need for the child depending on their stay and condition. It also depended on the school system and the teacher, if they are able to provide services in the hospital or at times the state will provide the children with an educator while they are hospitalized.

Only two people stated that they had been involved with children in school after they were hospitalized. They both went to a meeting at the schools for two children who were diagnosed with cancer. One social worker said that she was present at this interdisciplinary meeting upon request of the family and the connection she had with the child. After that she never had contact with the school system, but did stay in touch with the family after the girl

was in remission. Three left this question blank, and the other five reported they had to contact with the schools, at any level.

In response to one question asking if hospital supports were involved with the reintegration process to the community and schools, seven reported being involved with reintegration into the community. Some community reintegration programs included involvement in support groups for children with sickle cell/cancer, and helping families with their financial needs. There are support groups for children with HIV/AIDs and there are programs for mothers with sons who have hemophilia.

#### *Discussion*

Chronic illnesses such as cancer, sickle cell anemia, HIV, hemophilia and metabolic disorders, have a complex impact on the social, emotional, and physical development of children. Even after the medical aspects of these illnesses have been managed children with these disorders are susceptible to developmental and cognitive delays, along with ongoing concerns about physical responses of the body (Hayman, Mahon, & Turner, 2002). Many teachers will witness first hand the challenges that these students face in the classroom, and can be agents of support for students if they are more aware of the potential effects of the diseases (Wishnietsky & Wishnietsky, 1996). Most students experience psychological and social pressures, but having a chronic illness and dealing with reoccurring medical procedures and hospitalizations can exponentially increase feelings of worry and hopelessness.

The purpose of this study was to explore the relationship between hospitals and school systems and the outpatient support they provide for children with chronic illnesses. It was hypothesized that many children with chronic illness will face multiple setbacks (both emotionally and physically) that create obstacles to their transition back into the school

system. The literature supports the idea that children with a chronic illness may develop social, emotional, and cognitive delays because of their medical condition (Drotar et al., 2006; Hayman, et al., 2002; Wishnietsky & Wishnietsky, 1996). However as indicated by the results of this research and various references in the literature, individual children react differently to these social and emotional concerns, and depending on the severity or type of condition each child faces their levels of pain, rates of hospitalization and school absences will differ.

Based on the responses of the surveys distributed, a majority of the nurses, social workers and psychologists in the schools indicate there is a need for medical and educational support within the school system, but that there is not a high prevalence of children with chronic medical condition for which they are providing social and emotional support.

In the sample of 14 school personnel, it was interesting to see that many had not worked with the child's hospital provider at all. In fact only the school nurses had been in contact with the child's medical providers. Based on the responses, it is fair to say that academic and medical support needed however answers from participants displayed that the need is not large enough in each school to develop a specific social and emotional program for children returning to school after being hospitalized.

In addition it was hypothesized that there is not enough communication between hospitals and school systems during the child's hospitalizations and transition back into the community. The responses from survey participants supported this hypothesis. Ten respondents from the school system reported that there was no contact person that communicated with the school and hospital on behalf of the child. The majority of the hospital personnel also responded that they did not have a hospital/school liaison. This

suggests that one way to build more support for children who are dealing with a chronic condition is consider a hospital/school liaison that would support the child in both settings.

With better communication between hospitals and school systems, information about needed supports and emotional interventions employed within the hospital could be considered in transition back into the classroom and community. Hospital personnel who were participants in the survey identified key outpatient programs to support children and their families throughout their treatments. Many hospital social workers/ personnel reported that they engaged with families and the school only when families request them to be a part of the process.

This study looked at the effects of chronic illness and the needs of children from two different settings. In the school setting there are issues that the school social workers, psychologists, and nurses need to address on a daily basis (Keene, 2003). These professionals' experience working with children with a chronic illness can be rare, or is inconsistent from year to year. Therefore the need for programs and interventions for children with chronic illness are addressed with individualized plans that do not incorporate the other children in the classroom. As Hayman (1994) studied with participants in his research, there is limited education for teachers and school personnel on the effects of chronic illness on children and how to help a child in the classroom to be able to socially reacquaint themselves to their peers. Since there is a lack of knowledge about these unique concerns for children with a chronic condition, some teachers and/or school social workers may not be able to fully understand how to adequately help these children. Information such as results from studies on children with cancer have found that these survivors had; reoccurring fears about their cancer returning, desires to live normal lives, and a need to

mend relationships with peers (Hayman et al., 1994) would be useful for teachers to be aware of within the classroom.

The responses to the social and emotional needs of children with chronic conditions between school and hospital participants may have differed due to the lack of education about these conditions, and their prevalence in children. It seems there is a difference in the perceived impact that these illness have on a child, between school and hospital personnel. School personnel are not exposed to as many cases of children with a chronic illness and cannot be expected to be knowledgeable in all areas of need. Conversely hospital personnel are working directly with a concentrated group of these children and have become familiar with their needs and expert in managing their care. It can be suggested that as hospital personnel have developed great expertise in the management of children with chronic illness and their ongoing needs that they would be best suited to assume the role of liaison to outside agencies, especially schools (Keene, 2003). This would support the successful transition of children back to their activities of daily living. For a child with a chronic illness who has been hospitalized, returning back to school can feel like a return to normalcy for the child and for school personnel, knowing what to expect and how to manage issues can make the students return to school a more positive experience (Hayman et al. 1994).

In a study on the effects of chronic conditions for children a young man Eric A. stated (Keene, 2002):

“I made it through cancer, but almost didn’t make it through the first grade-and spelling. I studied every night, but I failed every test...what I wanted to tell my teacher was: *Please know that I do need help. But please don’t make me look different; I just want to be like everyone else* (p.336).”

These children do not want to be classified as different, but are likely to need help in specific areas. There are key components needed for children’s school re-entry plan. The school



social workers and psychologists, along with teachers should be educated further in the child's disease and treatments and how they may be affect the child within the classroom or limit his/her ability to function socially or academically. In addition there should be a team comprised of both hospital and school personnel that evaluate the child's medical, academic, and psychosocial strengths and needs (Keene, 2002). Although this study did not identify an overwhelming presence of children with chronic illnesses in the classrooms, each school participant surveyed said that they had worked with at least one student with a chronic condition at one point in their career.

In looking at the results of this study, some limitations can be identified. First, the sample size was small with only 24 participants; fourteen from schools and ten from the hospitals. This is not a sufficient sample to make generalizations about findings in relation to all hospital and school settings. In addition this study was more exploratory, statistical observations could not be made because many of the participants gave extended responses to the surveyed questions, so data could not be fully condensed and generalized within the sample. Still the idea of looking at both hospitals and schools strengthened the ideals and theories behind interventions for children dealing with a chronic condition.

Overall the study had several strengths. It opened many doors for exploration in both the hospitals and schools surveyed. Also the surveys showed that there were many positive programs that were forming for children with chronic conditions to support them in their transition back into schools. The present interventions for children with chronic illnesses can always be built upon to strengthen support for the child (Keene 2003). At school adults can make the environment as stress free as possible for children. In addition stress coping skills can be taught to all children and extra time should be spent to help understand and reduce

stress. It is important that these children have good transition plans to help with their transition into the classroom. When there is a team of people involved in a child's education and social and emotional wellbeing, children can return to a comfortable classroom setting.

Returning to school is difficult for any child, but there has been more positive outcomes for children who have receive support from the collaborative work of schools, families and hospitals (Wishietsky & Wishietsky, 1996). Further studies can be done with children in implementing new transition models that include hospital/school liaisons and collaborative team meetings.

Social workers intervene in the lives of children with chronic conditions at many stages, for emotional and social support. One of the key components of social work practice is communication, communication between themselves and clients, and communication between clients and their community. With effective communication and an established healthy relationship between the worker and clients, social workers can act as mediators and supports during any process of change or need (Keene 2002). Direct support and counseling from social workers to children and their families during the process of reintegration from the hospital settings back into the home and school environment would be an effective support to assist families in taking the skills learned in the supportive settings (i.e. Hospitals, etc) and applying them to their environment. Forming and maintain that relationship for the child is a way to advocate for their needs in the classroom and hospital setting (Keene, 2002).

This link for children would create an opportunity for caring over coping strategies and awareness of medical needs from the hospital to the school systems. Social work practice with children affected by a chronic condition should include increasing awareness and

development of education for families and schools of the short and long-term obstacles these children face after receiving medical treatments.

Even though some of these children receive IEP/ or educational plans within the schools, new policies should be advocated for in the schools to incorporate these children's individual needs (Keene, 2003). Policies within the classrooms should unify the students, if a child is unable to participate in a physical activity, and then there should be modified activities that include all the students. In this sense no child would feel like that are an outsider in their own classroom and could participate in the same way all the other children can. These efforts should involve ensuring that these children are not hidden below the radar and are given all the opportunities that other children receive.

Policies can be implemented in the classroom to aid and provide the child and his/her family with options. Under the Individuals with Disabilities Education Act, children should receive services to promote "vocational evaluations". If these children are having learning difficulties they have the right to special education or other related services within the school system. With something like an IEP in place for a child struggling academically these children can be a part of a smaller class with specialized services. Planning in the early stages after a diagnosis will provide a child with extra support. Policies and laws are "a tool to achievement and opportunity-make the law for you" (Keene, 2003, p. 205).

Further research can be done on the emotional needs of children with these chronic conditions. In addition further studies can be conducted see the prevalence of children with chronic conditions in schools. By understanding a child's point of view on chronic conditions, researchers would be able to implement further programs (if needed) that are designed by children and families who are experiencing these struggles first hand (Keene,

2002). Further research on hospital-to-home and school transitions can be facilitated to emphasize home and family involvement that includes self-management strategies, flexible school days, and increasing understanding of the illness. With the consistent help, communication and treatment from social workers, the child's illness may be effectively integrated into his or her family and school life (Kliewer, 1997).

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## *Appendix A*

### **Consent Form**

Dear Potential Participant:

I am a Social Work major at Providence College, completing her Thesis on the effects of hospitalization on children with chronic illness's social and emotional development in school systems. I am interested in the prevalence and needs of children with chronic illness. My plan is to look at a sample of public schools and hospitals in the New England area that have a leading medical center that specializes in care fore children with chronic illnesses like cancer, sickle cell, metabolic disorders, HIV/AIDS, and hemophilia. The ultimate question I am looking to examine is what does the follow-up transition processes look like for children when they leave by are still in need of medical and emotional support? The data and information that I gather from this study will be reported in a professional paper for my class.

Participation in this study will involve filling out a questionnaire about your self and the either the school system or hospital where you work. There are not anticipated risks associated with this study and any information that I receive will remain anonymous and confidential. I will not be using any personal names or the names of the institutions where you work. The findings within the study will be group together and from there I hope to be able to analyze the results.

Participation is voluntary. As a participant you are free to cease participation in this study at any time. Your confidentiality will be protected by storing the signed consent form separately from the data obtained by the study.

**YOUR SIGNATURE INDICATED THAT YOU HAVE READ AND UNDERSTOOF THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY AND YOUR PARTICIPATION WITHIN IT.**

Thank you for participating in this study  
Christina Marchitto, Undergraduate Social Work Major  
cmarchit@friars.providence.edu

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(Name)

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(Date)

**Attached below is the Questionnaire. –Thank you**



## *Appendix B*

### Survey Questions for School Personnel

#### **Background Information**

Gender:

Educational Background:

Degree:

Position within the School System:

#### **Demographics of the school:**

1. How what is the average census of the school, i.e. how many children attend the school?
  
2. What is the ethnic break down of the school?
  
3. What support personnel work in the school (i.e. Schools Social workers, guidance counselors, school psychologists)? If you do, how many hours a week is he/she available to the children?
  
4. Do you have a school nurse? How many hours is she/he available?
  
5. Is there a contact person in the school that deals with children's social and emotional issues in and outside of the classroom? If so, what is their title or position?

***If the response to this question is none, you do not need to complete the following questions within the survey.***

Have you or do you currently work with students that have a *chronic illness*, such as cancer, sickle cell disease, HIV/Aids, hemophilia, or any type of metabolic disorders including diabetes? (If possible, list the specific chronic illnesses and what you see them for)

***Please circle the answers below and fill in additional information when needed***

1. Have these students had a plan in school that either adjust to or allows for medical treatments?  
Yes or No
2. If a child with a chronic illness is out for an extended period or hospitalized do you receive any contact from the student's hospital or primary care provider?  
Never Sometimes Always
3. Does the school have a contact person or a liaison that works and communicates with both the school and the hospital setting?  
Yes or No
4. Do you have any programs in the school that address the unique needs of children with a chronic illness? (If Yes, could you explain a little about them?)  
Yes or No
5. Is there a standardized approach to transition children back into the school community from a hospital/ medical setting?  
Yes or No
6. Are there meetings that include interdisciplinary teams that care for the child coming back into the school?  
Yes or No
7. Do you think there is a need for more supports or interventions within the school system for children with chronic illness?  
Yes or No
8. Is there a plan to provide academic modifications or accommodations for these students?  
Yes or No
9. If yes, do these students or have these student had a 504 plans or a written Individual Evaluation Plan (IEP)?  
Yes or No
10. Does the school address any social and emotional disturbances of students with chronic illness? (If so how is this addressed within the school community?)  
Yes or No

11. Do you think programs for children with chronic illness would be necessary in the school?

Yes or No

12. Would they be successful in helping children make a successful transition from hospital to the school setting?

Yes or No

*Do you think having a chronic illness affects a child socially? Academically?*

## *Appendix C*

### **Survey Questions for Hospital Social Workers**

#### **Background Information**

Gender:

Title:

Position Within the Hospital:

Average amount of hours you work per week:

1. How big is the Hospital you work in?
2. What percentage of children served are preschool age?  
What percentage of children served are school age (5-12)?  
What percentage of children served are teenagers?
3. Are patients that you serve local or are the majority of the patients you see from a greater distance outside of the local school district area?
4. How many children are treated at the hospital for a chronic illness; HIV/AIDS, sickle cell, cancer, metabolic disorders, or hemophilia? (If possible could you give a breakdown for each)
5. On average how long are these children hospitalized or patients of the hospital?

Children with:

- a. HIV/AIDS:
  - b. Cancer:
  - c. Sickle Cell:
  - d. Metabolic Disorders:
  - e. Hemophilia:
6. Do you have programs in place that address the social and emotional needs of children and their families?  
  
Yes or No
  7. Are there support groups for children with chronic illnesses? Individual groups? Outpatient services? (Please Indicate which ones and types of services if the answer is Yes)  
  
Yes or No

8. Are there social workers or therapeutic intervention available to children in the primary care provider setting/ outpatient setting? If so, to what extent are these social workers available to the children?

Yes or No

9. Do you have a liaison or contact person who communicates with the school systems of these children?

Yes or No

10. Are these children typically referred to outside providers for social and emotional treatment after their discharge?

Yes or No

11. While in the hospital do patients receive any educational services?

Yes or No

12. Do you have a liaison or contact person that communications with the school systems of the children who are hospitalized? i.e Is there contact between hospitals and school nurses? Or school social workers/guidance counselors/ or school psychologists? (If so who is involved)

Yes or No

13. Are hospital personnel involved in the child's reintegration process to the community and school systems? (If so, then how are they involved)

Yes or No

***What are your thoughts on the social and emotional ramifications of childhood chronic illness?***