

**MANAGING PEDIATRIC CHRONIC ILLNESS IN THE SCHOOL SETTING
IN EASTERN NORTH CAROLINA**

by

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Abstract

Chronic pediatric health conditions include “long-term physical, emotional, behavioral, mental, and developmental disorders that affect a child’s functional state and require prescription medications and medical or educational services” (National Association of School Nurses, 2012). Approximately twenty percent of the children and youth population in the United States are diagnosed with chronic illnesses (Rivkina, et al., 2014). These chronic illnesses create daily struggles not only for the children, but also their families, friends, and others with whom the children spend time. Since education is an integral part of childhood development, it is important to understand how chronic illnesses are managed in the school setting. Best case management practice involves individualized, goal-oriented interventions such as direct nursing care, teaching, and counseling, and is based upon input from the student, family, teachers, and school nurse. A program evaluation was conducted to assess the program and the barriers and facilitators for chronic illness case management in an elementary school in eastern North Carolina. Three key informants responded to a questionnaire, and a school nurse record review was conducted. Findings included the most common chronic illnesses managed at the school, as well as the most common barriers, underreporting and lack of communication. Neither the school policy nor the district policy included procedures for following up with unresponsive parents. Recommendations for these policies include providing the reporting and case management forms at “Meet the Teacher” night before school starts and at open house nights held during the year, sending forms home to be signed with report cards, and interdisciplinary follow-up.

Keywords: pediatric chronic illness, case management, barriers, school nursing

Managing Pediatric Chronic Illness in the School Setting

Chronic illness can be basically defined as “a health condition that lasts anywhere from three months to a lifetime” (American Academy of Pediatrics, 2015). However, this definition does not fully portray the devastating impact that a chronic illness can have on individuals, particularly children. For pediatric chronic health conditions, a more detailed definition includes “long-term physical, emotional, behavioral, mental, and developmental disorders that affect a child’s functional state and require prescription medications and medical or educational services” (Forrest, Bevans, Riley, Crespo, & Louis, 2011, p. 304). These chronic illnesses create daily struggles not only for the child, but also their family, friends, and others whom the child spends time with. Since education is an integral part of childhood development, it is important to understand how school nurses manage chronic illness in the school setting.

This senior honors project was completed at an elementary school in eastern North Carolina in conjunction with the core community health course in a baccalaureate nursing program. Students are assigned to work with a registered nurse (RN) preceptor in a community-based health care setting for a clinical practicum experience. During this practicum, data collection and analysis were conducted for the purpose of comparing the school nurse’s chronic illness case management program with best practices identified in the literature. The honors project also met the course requirement of a Community Service Learning Project.

Background and Significance

Ten to twenty million children in the United States are diagnosed with chronic conditions (American Academy of Pediatrics, 2015). Those millions equate to almost twenty percent of the child and adolescent population (Rivkina, et al., 2014). Healthy lifestyle habits and health screenings can prevent the development of chronic illnesses including type two diabetes, heart

failure, obesity, and several others. However, some of the most common pediatric chronic conditions such as asthma, type one diabetes, cancer, and neurological disorders cannot be prevented (Berninger, 2015). In these cases, when prevention is not possible, the primary focus is management of the illness. According to a report from the Health Care Cost Institute (2012), children represent the fastest growing health care spending group in America. When a child is diagnosed with a chronic illness, the family's health care costs are increased tremendously. Dang, Warrington, Tung, Baker, & Pan (2007) concluded that for families that do not have the best insurance, school nurses can provide cost reduction by managing their child's chronic illness. Most children and adolescents spend a significant portion of their developmental years in school, away from their parents. Without parents present at the school to manage their child's chronic illness, the responsibility falls to the child, teacher, school nurse, and school administration.

In addition to managing the student's chronic illness through medication and direct health care interventions, school nurses also address other school-related, emotional, and quality of life complications that arise from a chronic illness diagnosis (Bonaiuto, 2007; Engelke, Guttu, Warren, & Swanson, 2008). For many children with chronic illnesses, these complications can be even worse than the actual diagnosis. One of the biggest issues surrounding a chronic illness is the number of school absences. The child's inability to attend school can affect their potential for educational success, school-reintegration and personal readjustment, ability to form close relationships with peers and teachers, and the child's potential for being a victim of bullying due to physical, mental, or emotional differences (Berninger, 2015; Bonaiuto, 2007; Dewalt, et al., 2015; Engelke, Guttu, Warren, & Swanson, 2008; Layte & McCrory, 2013; Power & Derosa, 2012). According to the Center for Managing Chronic Disease (2011), in 2008, pediatric asthma

alone accounted for more than 10.5 million days of school absences. Typically, along with the diagnosis of a chronic illness comes a social stigma, particularly with conditions that affect the child's appearance. Even without being bullied, the stigma of being different can be very emotionally exhausting. As reported by the American Academy of Pediatrics (2015) & DeWalt, et al., (2015), many children with chronic illnesses have generalized anxiety, and may experience depression.

Review of the Literature

Nursing Interventions and Case Management

Although the school nurse is trained to address students' physical health care needs, chronic illness case management programs allow the nurse to have a positive impact in all areas of the child's well-being. According to Bonaiuto (2007), a beneficial case management program tracks student attendance, behavior, academic performance, quality of life, and health compliance, providing interventions in various other areas as needed on an individual basis.

Several articles discussed case management programs for chronic illnesses. Keehner, Engelke, Guttu, & Warren, (2009) defined case management as "a process by which the school nurse identifies children who are not achieving their optimal level of health or academic success because they have a chronic condition that is limiting their potential, (p. 421)." and is based on input from family and teachers, and school nurse assessments. In the same study, they identified outcome measures and educational resources available for case management. Bonaiuto (2007) determined the benefits of a four-year school nurse case management process that tracked attendance, behavior, academic performance, quality of life, and health compliance in students. Students were selected as participants based on physicals, frequency of visits to nurse's office, presence of chronic illness, student services team meetings, teacher, staff, parent referrals about

health concerns, and attendance issues. After individualized, goal-oriented interventions such as direct nursing care, teaching, and counseling, students from each year showed significant improvement in their attendance, behavior, academics, quality of life, and health compliance (Bonaiuto, 2007). The improvement supported the effectiveness of case management, which allowed the study to continue, and more students to be added to the program.

Garwick, et al. (2015) conducted a study that actually resulted in the development of an international school nurse care coordination model. The goal of the research was to identify and compare how school nurses in Iceland and Minnesota coordinate care for students with asthma and also develop a care model based on school nurses' responses to open-ended interview questions. These questions related to care management with students, parents, healthcare providers, and other school personnel. The interviews resulted in a standardized care coordination process comprised of information gathering, risk assessments, prioritizing health needs, and anticipating and planning for students' needs (Garwick, et al., 2015). This process was further broken down into specific interventions including symptom management, case management, and education. Garwick et al. (2015) reported that universal health care eliminated health disparities in Iceland, whereas in Minnesota, the population was far more diverse in the range of access to health care. In Minnesota, school nurses spent more time on the individual interventions of symptom management and students' needs rather than interdisciplinary interactions.

Multidisciplinary programs. Managing a child's chronic illness involves numerous hands and minds. Several effective multidisciplinary programs were found in the research (Dang, Warrington, Tung, Baker, & Pan, 2007; Merianos, Vidourek, King, & Nabors, 2015; & Worchel-Prevatt, et al., 1998). A study conducted by Worchel-Prevatt, et al., (1998), involved a child's

reintegration into the school setting after a long-term hospitalization. Components of this program involved hospital and school personnel, and the child's family. Within the hospital and school, liaison teams were formed to best communicate with one another about the child's healthcare and other needs, with the hospital team concentrating primarily on determining potential health barriers for returning to school, creating goals, and communicating with the school nurse (Worchel-Prevatt, et al., 1998). The school personnel, including the nurse, focused on chronic illness education within the school to reduce the anxiety of teachers and classmates upon the child's reintegration. Worchel-Prevatt et al. (1998) collected data in the family-based component about the child's developmental level, their perspective of the illness severity, sibling reactions, and family coping mechanisms related to lack of knowledge and other stressors. The children used standardized ranking scales to evaluate their own self-esteem, emotional functioning, and their individual coping strategies. Worchel-Prevatt et al. found that these teams came together to formulate plans to easily and effectively reintegrate the student to school with minimal complications.

Dang, Warrington, Tung, Baker, & Pan, (2007), identified that in some cases, school nurses were given autonomy in their scope of practice to effectively combat the lack of, and sometimes superfluous, ADHD diagnoses in school-aged children. In collaboration with physicians, school nurses introduced a school-based framework for ADHD identification and management. The model Dang et al. (2007) created focused on four major steps: early identification and treatment, improved communication between schools and primary care providers, improved social and academic outcomes for students, and a reduction in the number of inappropriate referrals for ADHD. After the school nurse completes assessments on the students, if the results are significantly directed towards an ADHD diagnosis, the school nurse can refer a

patient to their primary provider. Dang et al. found that by allowing school nurses the range of practice to complete initial assessments, the diagnosis and treatment processes are accelerated, eliminating the need for more initial visits to the primary provider.

Barriers to Managing Chronic Illness in Schools

To begin the process of creating, or improving, a management program, barriers to progress must be identified. Some important things to determine are obstacles in the process of reporting these illnesses, barriers surrounding school reintegration for the student after long-term absences, and actual complications in the school nurse's management of the illness during the school day (Rivkina, et al., 2014).

In order for a school to efficiently help a child manage a chronic condition, the teachers, nurse, and administration should be made aware of the diagnosis, medications, and needed interventions. The beginning phase of any illness management is the child's diagnosis. Depending on the type and severity of the illness, the diagnosis may take a long time, with trips to specialized physicians. If a child's parents do not have insurance or the knowledge or support to take their child to these appointments, the diagnosis may be delayed even longer, negatively impacting the child's well-being (Dang, Warrington, Tung, Baker, & Pan, 2007). Engelke, Guttu, Warren, & Swanson, (2008), found a correlation between minorities, lower socioeconomic families, and higher incidences of pediatric chronic illness. Specifically, they found that 54% of the students identified as having chronic illnesses were minorities, and 63% were considered from low-income families. Engelke et al. (2008) speculated that minorities and low-income families may not have access to the specialized health care or adequate insurance to cover their child's illness, which could delay doctor's appointments and overall diagnosis.

After a child is diagnosed with a chronic illness, the reporting process begins with the parents obtaining a physician's note to the school describing the diagnosis and child's medical needs. Another early step that involves complete parental interaction includes meetings with teachers, school nurse, and other school personnel to outline care for the child and other needed interventions. These school meetings will result in a 504 Plan, based on Section 504 of the Rehabilitation Act of 1973, which exists to "prohibit discrimination on the basis of disability in programs and activities, public and private, that receive federal financial assistance" (Disabilities Rights, Education, and Defense Fund, n.d. & KidsHealth, 2015). In the chaotic aftermath of a chronic illness diagnosis, it is difficult for families to know which steps to take first. Implementation of reporting processes make it easier for parents to determine where to go for assistance (Rivkina, et al., 2014).

Communication. Communication is a key component in effectively managing children's chronic illnesses at school. Effective communication from parents and school personnel can result in optimal management of a child's chronic illness and avoid several complications.

Parental involvement is crucial for the school to manage their child's chronic illness. In several studies, the researchers and school nurses reported that they found parents to be uninvolved, offering no support to the school or their own child, and sometimes unwilling to even communicate. (Botcheva, Hill, & Kane, 2004; Dang, Warrington, Tung, Baker, & Pan, 2007; Engelke, Guttu, Warren, & Swanson, 2008; Engelke, Swanson, & Guttu, 2014; Keehner, Engelke, Guttu, & Warren, 2009; Rivkina, et al., 2014). Rivkina, et al. (2014) identified that the Chicago Public School System requires parents to pick up their child's report cards, creating an opportunity for communication about the illness. When parents come to the school, they take surveys that ask about any changes in their child's health care needs. If a parent needs to discuss

a new diagnosis requiring school interventions, nurses are available to record responses and help parents navigate the complex process. Rivkina et al. noted that through this required parental interaction with the school, accurate health records were obtained, ensuring the child's well-being.

Even with sufficient support from students' parents, a lot of the responsibility of communication falls to the school nurse. Two articles discussed school nurses asking for suggestions throughout the year (Botcheva, Hill, & Kane, 2004; Dang, Warrington, Tung, Baker, & Pan, 2007; Engelke, Swanson, & Guttu, 2014). The school nurses sought out parents' perceptions of how they feel their child's illness is being managed. Engelke, Swanson, & Guttu, (2014), evaluated parents' opinions of the impact that nursing interventions made on their child's educational success, or if they felt there was any at all. Since parents had to volunteer for this study, the sample was small, and the results were classified as insignificant. Dang, Warrington, Tung, Baker, & Pan, (2007), looked at parental perception of school-based management programs focused on the effectiveness of reintegration programs after long-term school absences. Dang et al. assessed the recovery stages of exacerbations of chronic illness as well as the parents' perspectives of school reintegration services at the different stages. The researchers conducted telephone interviews based on four categories of complications: academic performance, school adjustment, self-esteem, and social relationships. At the time of entry into the program, parents reported being very concerned about their child's school adjustment and self-esteem, and somewhat concerned about their social relationships. The highest area of concern was for their child's overall functionality. Dang et al. found that after the child had been established into the program, at the time of interview, there were significant decreases in all categories, with parents reporting the effectiveness and helpfulness of the school reintegration program. These studies

highlight the importance of effective communication to benefit the children and decrease the prevalence of potential complications from chronic illness.

Continuing Education for School Nurses

Nurses play a significant role in educating students with chronic illness diagnoses, their parents, teachers and school personnel, and other students as peers. According to National Association of School Nurses, (2012), with technological advances, children with chronic health conditions are able to improve their school attendance and succeed due to the support service provided mainly by school nurses. With growing numbers of these students in public schools, their health conditions pose a challenge for parents, school nurses, administrators, teachers, and health care providers. Since there is not a class on this specific topic, school nurses do not have opportunities to become well versed in management of pediatric chronic illnesses. The National Association of School Nurses, (2014), stated that “the quality of nursing practice is directly linked to the practitioner's body of knowledge and level of skills” (para. 1).

Sprague-McRae & Rosenblum, (2013), published an article regarding the issue of school nurses not having sufficient knowledge, or confidence in their understanding, of chronic, neurological health conditions. Sprague-McRae & Rosenblum, (2013), conducted a study that was comprised of surveys completed by school nurses on the subject of chronic illness. After analyzing the responses, the researchers found that there was a need for continued education for school nurses in the area of managing chronic conditions. They combined a few different management models into a continuing education workshop curriculum for school nurses throughout California. Sprague-McRae and Rosenblum discovered the school nurses found it to be beneficial, and the program was expanded with hopes to offer the educational workshops throughout the entire country. The study implies that school nurses are lacking in knowledge and

understanding of students' chronic, neurological conditions, but offers a solution in the form of continuing education workshops.

Jones, Brener, & Bergen, (2015), evaluated school system policies in relation to school nurses managing chronic illnesses. Researchers wanted to know if the district policies had any requirements to provide health services to students with chronic illness, and if those policies related to more funding of professional development for school nurses. Jones, Brener, and Bergen compared different school districts' policies and the likelihood of funding continuing education courses for school nurses. The results showed a direct correlation between districts policies requiring schools to offer services, and funding professional development for school nurses. This study provides an aspect of bureaucracy that is not typically considered.

Methodology

Setting and Sample

This honors project was completed throughout the seven-week community health clinical component of my last semester in nursing school. In this class, we have lecture two days each week, but also complete 87 hours of clinical experience with a public health nurse preceptor in a community health setting in eastern North Carolina. My particular community health nursing experience was with a school nurse in a kindergarten through fifth grade elementary school.

This project took place in a county in eastern North Carolina with a large military presence. Since all military personnel and their families have access to health care through the military, there are fewer health disparities in that part of the county as compared to the surrounding counties. Through the windshield survey, I noted several health care clinics, both primary care and specialties. However, all of the clinics in in the area are grouped in certain areas of town. For citizens that do not have transportation, access to health care becomes a

definitive issue. Since there is a large military presence in the community, ages, as well as races, vary tremendously. From infants to elderly, Caucasian, African American, Asian, and Middle-Eastern, all populations are represented in this county. According to the NC State Center for Health Statistics, the top three leading causes of death in the county are the same as North Carolina overall: Cancer, Heart Diseases, and Chronic Lower Respiratory Disease (NC State Center for Health Statistics, 2015). Teenage pregnancy is also a very significant issue in this county. In 2013, six girls became pregnant each week, which sparked a county-wide initiative in 2015. Two more county health priorities are tobacco use and obesity, in which this county has scored worse than the overall North Carolina percentages.

The elementary school I was assigned is a large elementary school, ranging from kindergarten to fifth grade. The school was centered between two very nice neighborhoods. The majority of the school population is Caucasian, and there are few health disparities within the school due to the majority of students being from military families. There are approximately 800 students at the school, with a quarter of those students having chronic illness care plans on file with the school nurse. My project was to evaluate the process for creating these care plans, evaluate existing care plans for common illnesses, and compare to evidence-based best practices.

Data Collection

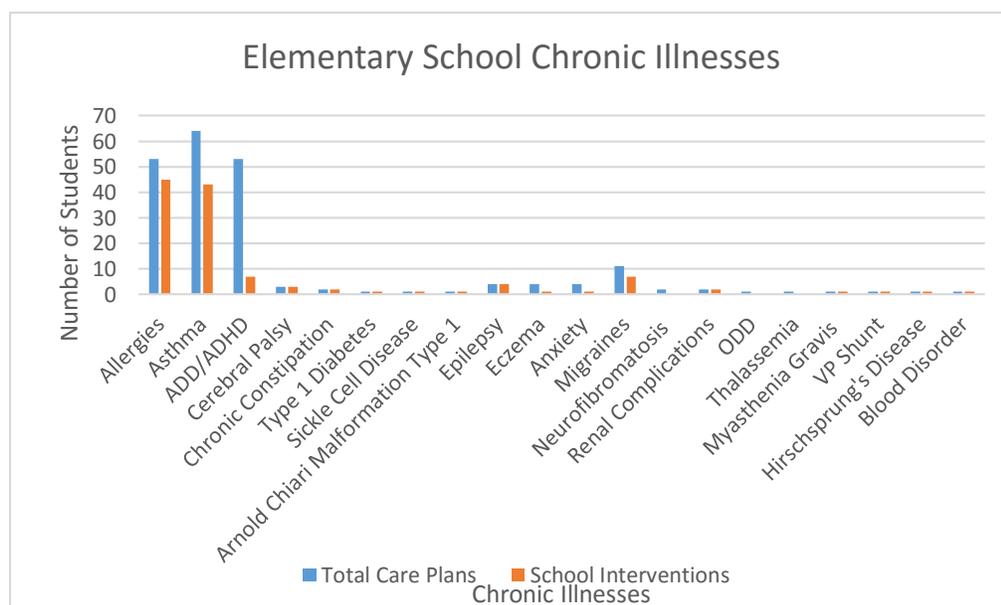
After observing, and participating in, the interdisciplinary collaboration, I identified three key informants regarding my project: the school nurse, the guidance counselor, and, the social worker. I discussed with each of their critical roles in managing students' chronic illnesses. I asked the informants their perceptions of the current case management program, as well as their perceptions of barriers to effective management of students' chronic illnesses. Using the evidence surrounding barriers to case management found in my literature review, including lack

of communication, insufficient education among nurses and school faculty, underreporting by parents and guardians, and potential health disparities due to socioeconomic status, I asked the questions in a checklist format. Following discussion, my preceptor and I gathered secondary data by analyzing student medical files. After all the data was collected, I developed tracking tools that enabled me to identify the most common chronic illnesses within the school and the different types of management the students receive. I also assessed different policies guiding how to address students’ chronic medical needs, and I compared the policies to the evidence-based practice case management programs identified in the review of the literature.

Findings

After discussing case management with the three key informants and reviewing the nurse’s records, I developed a graph (see Figure 1) to identify the most common chronic illnesses that students face at the school. I compared the number of forms on file with the nurse, to the resulting number of interventions provided to the student. I then compared the types of interventions to evidence- based practice.

Figure 1. Chronic Illnesses and Number of Interventions



Among the approximately 200 students with documented chronic illnesses, most care plans referenced allergies and asthma, and students already had asthma action plans in the classroom. However, there are other chronic illnesses that require the nurse's attention, as well as teacher and peer education, including sickle cell disease, ADHD, cerebral palsy, epilepsy, and several other conditions. When a child's parent sends medical forms to the school nurse, if the condition is not common, a customized care plan must be created, and education must be provided to teachers and other school staff. The most common school interventions included medication on site in the nurses' office, asthma inhalers and plans in the classroom, and special accommodations, specifically for testing purposes.

In comparison to the reviewed literature, the elementary school in Eastern North Carolina is largely following evidence-based practice. According to Bonaiuto, students have the best outcomes and greatest potential for success after individualized, goal-oriented interventions such as direct nursing care, teaching, and counseling (Bonaiuto, 2007). Within the elementary school, the school nurse, counselor, and social worker, are able to create individualized plans for students, which involve direct care and management, counseling, and teaching families of available resources. Establishing and following these care plans provide the students the best potential for success. In addition to the strong interdisciplinary team efforts, the school nurse provides a very individualized and organized documentation process with forms for each common chronic illness, and customizable forms for uncommon illnesses.

Common barriers found in the literature review include lack of communication, underreporting, and lack of education. They found these barriers to be linked with socioeconomic disparities. Researchers have found parents to be uninvolved, offering no support to the school or their own child, and sometimes unwilling to even communicate (Botcheva, Hill, & Kane, 2004;

Dang, Warrington, Tung, Baker, & Pan, 2007). At the elementary school, the key informants identified the largest barrier to managing the students' chronic illness is underreporting of illness. Despite the assistance provided by the social worker, the faculty believe the underreporting and lack of communication to be linked to lower socioeconomic status.

Limitations

The main limitation in this project was the sample and setting. Although the sample was large, it was not very diverse in terms of access to health care. The project intended to look more in depth at different socioeconomic status barriers, specifically different levels of access to health care. Since the school sample included primarily children from military families, military health insurance supported access to health care. If this program evaluation was conducted in another elementary school with children who experienced more limited access to health care, results may have been different.

Implications for Practice and Policy

When determining barriers to effectively managing the chronic illnesses within the school, I noted records of students with lack of health insurance documentation, those of students with no primary care provider on file, as well as those who had notes in their files regarding guardians being unresponsive to communication attempts from the school nurse. I was able to gather information that supports the faculty's belief that the underreporting, lack of communication and lack of overall parental involvement stems from socioeconomic disparities. Based on the literature review and the evaluation of the school's case management program, attempts should be made to establish policies that directly address the issue of underreporting and lack of communication. Parents may be provided with the reporting and case management forms at "Meet the Teacher" night before school starts, as well as at open house nights during the

year. To address the school nurse's belief that parents are tired of filling out forms, the forms may be sent home with report cards, to decrease the frequency of information going home to parents throughout the year. Efforts should also be made to combat the complications from socioeconomic difficulties, such as, continuing to engage parents of students with the social worker. Instead of waiting for issues to arise, the social worker can work with the school nurse to identify at-risk students and be proactive in her approach and monitor those students. She is able to provide parents with information about available resources including CHIP, the children's health insurance program, the WIC program, Medicaid, and affordable housing.

All chronic illnesses create daily struggles, especially for a child. Children spend a large portion of their days in school, so they need to feel safe and secure with their illness. School nurses and other faculty have a responsibility to care for these children, providing nursing management, counseling, and compassion. Since case management has proven to improve student success, schools should establish plans that include effective case management practices.

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