Factors Impacting School Nurse Care Coordination for Children with Special Healthcare Needs

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Dedication

This dissertation is dedicated to my children, my sisters and my parents. Thank you for your support.

Abstract

Background: Children with special healthcare needs (CSHCN) compose a significant potion of pediatric clients. Approximately 14.2 million U.S. children have special healthcare needs. CSHCN are integrated into the school system to the level their disability allows. School nurses are responsible for the healthcare needs of these children while in school. **Purpose:** The purpose of the study was to explore the factors which impact school nursing care coordination of CSHCN. Six specific study aims were identified to support the research purpose. **Methods:** The design of this research was a qualitative descriptive study. Data were gathered during semi-structured interview with 27 school nurses from one Midwestern state. Participants described their experience with care coordination for CSHCN in their schools. **Results:** A total of 19 separate themes across the six study aims were identified. From the 19 themes identified there were four overarching factors which could encapsulate all 19 themes. Factors which impact school nurses' provision of care coordination for CSHCN are: school nurses need to establish relationships with a team; information needs to be collected and shared; each child has individualized plans to meet overarching educational goals; and sufficient time is needed. **Conclusions:** The school nurse participants in this study provided insights into the care coordination efforts they make on behalf of the CSHCN in their schools. Little research has been conducted about factors contributing to care coordination for CSHCN by school nurses. This study fills a gap in knowledge about school nursing and raises questions for future research about the understanding, contributing factors and barriers to effective care coordination by school nurses for CSHCN.

Table of Contents

Acknowledgements i
Dedication ii
Abstract iii
Table of Contents iv
List of Tables viii
List of Figures ix
CHAPTER 1 INTRODUCTION 1
Research Problem 1
Children with special healthcare needs in schools. 2
Care coordination across multiple settings. 5
Study Purpose 6
Research Question 6
Study Aims 6
Research Design Overview 7
Investigator's Background and Assumptions 8
Significance 10
Chapter Summary 12
CHAPTER 2 LITERATURE REVIEW 14
Search Strategies 14
Topics Addressed in Literature Review 15
Care coordination. 15
Care coordination in ambulatory pediatrics. 16
Impact of care coordination. 18
Providers of care coordination. 20
Care Coordination in the Educational System 23
School Nursing Outcomes Research 27
Conceptual Framework 40
Search strategies. 45
School nursing framework for practice in school nursing literature. 46
Chapter Summary 51
CHAPTER 3 METHODS 52
Study Aims 52
Participants 53
Recruitment summary. 55
Setting 56
Key Definitions and Terminology 57
School nurse. 57
Children with special healthcare needs (CSHCN). 57
Care coordination. 58
Terminology. 59
Research Design 59
Design features of qualitative description. 61
Data Collection Methods 63

Qualitative semi-structured individual interviews. 64
Demographic survey. 66
Field notes. 66
Data Analysis 67
Qualitative data analysis plan. 67
Coding scheme. 68
Qualitative analysis plan by study aim. 69
Quantitative data analysis plan. 70
Trustworthiness 71
Ethical Considerations 73
Chapter Summary 73
CHAPTER 4 RESULTS 75
Description of Participants 75
Description of CSHCN medical needs and family characteristics 77
Coding Scheme 79
Establishing Trustworthiness of Coding Scheme 83
Qualitative data analysis by study aim. 86
Study aim 1: Investigate school nurses understanding of care coordination and how they perceive their role in relationship to care coordination. 86
Collaboration. 86
Overarching goals. 88
Parents lead the way. 89
Informal identification process. 90
Advocacy. 92
Liaison to the community. 94
Assessment is foundational. 95
The school nurses identify assessment as a foundational step to all the other steps in care coordination. 95
Individualized planning. 95
Study Aim 2: Describe tools/ resources used for planning care coordination activities. 99
Information resources. 99
Seeking evidence. 103
Study Aim 3: Describe the systematic process used for planning and communicating care coordination activities. 105
Individualized care plans. 105
Templates for plans. 107
Individualized communication process. 108
Study Aim 4: Describe the impact of helping relationships on planning and communicating care coordination activities. 112
(Helping relationships are) essential to success. 113
Trust. 116
Study aim 5: Identify factors associated with facilitating care coordination activities. 120
Communication. 120

Support of a team. 122
Study aim 6: Identify factors which inhibit care coordination activities. 123
Time. 123
Access to information. 126
Factors impacting school nurse care coordination for CSHCN. 129
CHAPTER 5 DISCUSSION 133
Comparison to Literature 133
Factor 1: School nurses need to establish relationships with a team. 133
Collaboration. 134
Parents lead the way. 135
Advocacy. 136
Liaison to community. 137
(Helping relationships are) essential to success. 137
Trust. 138
Support of a team. 140
Factor 2: Information needs to be collected and shared. 141
Informal identification process. 141
Assessment is foundational. 141
Information resources. 142
Seeking evidence. 143
Individualized communication process. 145
Communication. 148
Access to information. 149
Factor 3: Each child has individualized plans to meet overarching educational goals. 151
Overarching goals. 152
Individualized planning. 152
Individualized care plans. 153
Templates for plans. 154
Factor 4: Sufficient time is needed. 155
Time. 155
Recommendations 157
Practice. 157
School nurses should not be responsible for more than 750 students. (time) 157
School nurses should develop a consistent approach to identification of students who might benefit from school nurse care coordination efforts. (informal identification process) 158
Consistent utilization of standardized nursing language in IHPs and the development of a translation of the nursing language into local terms. (individualized communication process) 158
Increase school nurses awareness of the available care plan templates. (templates for plans) 159
Education. 159

School nurses should have a clearer understanding of the SNFP, especially the concept of helping relationships. (helping relationship are essential to success) 159
Educate school nurses on use and development of evidence based practice guidelines. (seeking evidence)..... 160
Policy. 161
Primary care providers for CSHCN should provide an option for parents to sign an annual release of information statement including school nurses. (collaboration) 161
Accelerate the development of personal health records for CSHCN. (access to information)..... 162
Increase adoption of integrated electronic school records. (access to information) 163
Research. 163
Strengths and Limitations..... 164
Strengths. 165
Limitations. 166
Conclusion..... 167
References 170
Appendices 186
Appendix A. Invitation letter to potential participants. 186
Appendix B. School Nurses of Minnesota e-mail to members. 188
Appendix C. Script for telephone contact with potential participants..... 190
Appendix D. Semi-structured interview guide. 193
Appendix E. Collection of Survey Data 195
Appendix F. Agreement to participate statement. 197

List of Tables

Table 1	Recruitment summary	page 56
Table 2	Summary of demographic survey results	page 76
Table 3	Summary of node/sub nodes and the related study aims	page 80

List of Figures

Figure 1	School Nursing Framework for Practice	page 41
Figure 2	Qualitative data analysis process	page 85
Figure 3	Themes displayed by factor	page 131

CHAPTER 1 INTRODUCTION

In the last 30 years the characteristics of the educational system and the children served have altered dramatically to accommodate a special population of students, children with special healthcare needs (CSHNC). Growing up in the early to mid 20th century, CSHCN were often excluded from the public education system or placed in a state institution or hospital. Parents would play a peripheral role in directing the healthcare decisions for these children, most of the care being directed by the physician or the institution where their child would reside. Now these children live in the community and are integrated into the public school system. The parents assume a primary role in developing educational and healthcare plans for their children. Through all this change, one constant source of support for all school aged children has remained; the constant of the school nurse. The school nurse serves the entire school population regardless of the presenting condition or concern brought forth by the student or family. The school nurse brings extensive expertise and skills developed over time to care for and ensure these CSHCN are as fully integrated into the school system as their health condition will allow. This study explored the factors which impact school nursing care coordination for CSHCN.

Research Problem

Children with special healthcare needs compose a significant portion of the pediatric clients (Bethell et al., 2011). School nurses interact daily with CSHCN either directly through treatments, teaching or monitoring or indirectly through planning for care, directing other staff in providing care or communicating to other staff members the

plan to address the healthcare needs of these students. School nursing practice encompasses the health care coordination needs for all students. School nurses also interact and serve as a health resource to staff and community members touched by the school for which the nurse is responsible. The burden of responsibility for a school nurse is large, not only in the number of students or staff but in the increased complexity of the conditions and problems of their students. Little is known about what factors impact the school nurse's efforts to coordinate care for this group of students, CSHCN. An initial step is to understand from the point of view of the school nurse how care is coordinated within and across the complex educational and healthcare systems.

Children with special healthcare needs in schools.

It is estimated that 19.2% of U.S. children (approximately 14.2 million) and 14.4% of children in the state of Minnesota (Bethell et al., 2011; Child and Adolescent Health Measurement Initiative; Kogan, Strickland, & Newacheck, 2009) have special healthcare needs. Children who live with a chronic physical, developmental, emotional or behavioral condition requiring health related services beyond that of their healthy peers are defined as children with special healthcare needs (Newacheck et al., 1998; van Dyck et al., 2002). With improvements in healthcare it is now anticipated that 98% of children with chronic health conditions will survive to the age of 20, past high school graduation (Adolescent Health Committee, Canadian Paediatrics Society, 2006). These children might require assistance from the school nurse to manage and coordinate their healthcare needs to increase the likelihood they will be successful in school.

School absenteeism resulting from long term healthcare needs is one key problem identified for children with chronic health conditions. The absenteeism problem is

amplified as the child progresses through the school system to junior and senior high school where academic demands become greater (Adolescent Health Committee, Canadian Paediatrics Society, 2006). Frequent absenteeism impacts academic success, graduation rates and eventual employment as an adult (Kearney, 2003). School administrators have long recognized these serious, lifelong consequences and have made efforts to keep children in school to combat these concerns. State and federal laws require school attendance. Parents of Minnesota children age seven to sixteen are primarily responsible for assuring the child receives adequate knowledge and the skills to become an effective citizen (Minnesota Office of the Revisor of Statutes, 2010). Given these requirements and potential challenges related to school absenteeism school administrators and school nurses have instituted policies and programs to support student success.

School nursing practice began in New York City in 1902. Nurses focused efforts on reduction of school absenteeism through communicable disease prevention interventions (National Association of School Nurses, 2009). This approach was a public health initiative applied to an educational issue. As the face of the educational system has changed so has the role of the school nurse. The school nurse's expanded role now bridges the educational, healthcare and public health systems (National Association of School Nurses, 2009). Knowledge of federal and state laws related to educational accessibility influence how schools and school nurses develop plans for interventions and accommodations required for CSHCN.

In 1975 the first federal law, Education for All Handicapped Children Act (EHA), was enacted to support states and localities in their efforts to protect the rights of all

children with disabilities. In 1990 the EHA was renamed as the Individuals with Disabilities Education Act (IDEA). Amendments to this act have been made with the most current revision signed into law in 2004. This law established the standards for the free and appropriate public education for CSHCN. Additionally this law defined which types of support or related services are to be provided to CSHCN so they might receive an appropriate education. These services must be provided for children from ages of 3 to 21. Plans for these services are documented in two types of plan: the Individualized Family Service Plan (IFSP) for children ages 3-5 and an Individualized Education Plan (IEP) for children ages 5-21 (National Association of School Nurses, 2006a). In these plans the related services required (including speech therapy, physical therapy, occupational therapy, audiology, psychology, recreation therapy, rehabilitation counseling, mobility services and medical care) and any needed accommodations are clearly articulated (American Academy of Pediatrics, 2007). The school nurse manages the medical care needed for the CSHCN while attending school in accordance with the state's nurse practice act. In some instances the school nurse delegates responsibility to other school personnel but ultimately assumes responsibility for coordinating the care received in the educational system for all students but especially for those students with chronic health conditions (National Association of School Nurses, 2006b). The school districts and school nurses are bound to follow these plans in accordance with the federal regulations. The school nurse then develops healthcare related plans that specify the healthcare actions needed to meet the educational needs of the student.

The pressures of increasing numbers of students with chronic healthcare needs and legal challenges placing the burden of caring for CSHCN on the schools has

increased the burden on the school nurse to deliver appropriate care using available and often limited school resources. Coordinating and communicating the healthcare needs of students is the responsibility of the school nurse (National Association of School Nurses, 2005). Often these healthcare needs require a skilled licensed school nurse or they might be performed by other school staff within the school under the direction of a school nurse (Heller, Frederick, Best, Dykes, & Cohen, 2000). A method must exist to coordinate who, where, when and how healthcare needs for CSHCN are delivered to these children while in the school. This is the role of the school nurse as a care coordinator.

Care coordination across multiple settings.

The school nurse works across multiple healthcare, public health, insurance and school systems but primarily focuses care coordination activities to meet the needs of students within the educational system. There are a number of qualitative studies where parents or caregivers of CSHCN were interviewed about the challenges they face in coordinating care across multiple settings (Anderson, 2009; Garwick, Kohrman, Wolman, & Blum, 1998; Lindeke, Leonard, Presler, & Garwick, 2002; Lutenbacher, Karp, Ajero, Howe, & Williams, 2005; Miller et al., 2009). In general, schools were mentioned as one setting which must be considered when attempting to coordinate care but schools were not the primary site responsible for care coordination. Parents recognized schools during early childhood intervention programs as providing strong support for coordinated care in children age 0-3 but after that age, support from schools was inconsistent at best, services were lacking or inconsistently delivered, and there was poor communication to the parents (Lutenbacher et al., 2005). School nurses were recognized as being involved in the planning, delivery and coordination of care

(Anderson, 2009; Miller et al., 2009) but parents did not identify how nurses were able to communicate the care coordination activities to them or others within the school. Parents did recognize that an Individualized Education Plan (IEP) prepared by the school might address healthcare needs (Lindeke et al., 2002), but care coordination is not typically addressed within the IEP. One study suggested improved training for health care professionals would enable health professionals and school nurses to provide high quality care for CSHCN. This training was not only focused on school personnel but healthcare providers throughout the community (Garwick et al., 1998). Generally parents recognized there were challenges to coordinate care for their child across multiple settings in the community including schools.

Study Purpose

The purpose of the study was to explore the factors which impact school nursing care coordination of CSHCN. This research serves as foundational research necessary for further investigation of school nurse care coordination processes and possible solutions to improve the process of care coordination for CSHCN.

Research Question

The research question for this study was: What factors impact school nurses' ability to perform care coordination activities for CSHCN?

Study Aims

The study aims were to:

- Explore school nurses' understanding of care coordination and how they perceive their role in relationship to care coordination

- Describe tools/ resources used for planning care coordination activities
- Describe the systematic process used for planning and communicating care coordination activities
- Describe the impact of helping relationships on planning and communicating care coordination activities
- Identify factors associated with facilitating care coordination activities
- Identify factors which inhibit care coordination activities

Research Design Overview

This study was a qualitative descriptive study. The purpose was to explore the factors which impact school nursing care coordination of CSHCN. Qualitative descriptive studies were distinguished from other qualitative designs by Sandelowski. She writes that qualitative description is "a comprehensive summary of an event in the everyday terms of those events" (Sandelowski, 2000, p. 336). The difference between other qualitative designs and qualitative description is the lack of interpretation or implied meaning imposed upon the data during analysis. The researcher does not analyze the data with an eye to a preconceived framework nor does the researcher seek to test a theory as part of the analysis. The researcher seeks to objectively report the findings in everyday terms common to the population or event under investigation.

The method utilized to explore the factors which impact school nurses' ability to perform care coordination for CSHCN was individual semi-structured interviews. The investigator followed a content analysis approach (Krippendorff, 2004) for the analysis of

the transcribed interview data. The analysis was supported by the researcher's journal and member checking for confirmation of the coding scheme which is foundational for trustworthy reporting of the study findings.

The investigator sought to engage school nurses from a variety of locations, across school district sizes from large to small and across student age ranges from primary to secondary schools. This variety of working environments allowed for the capture of a wide range of school nurse experiences. Semi-structured interviews were conducted to determine what factors impact the school nurses' ability to perform care coordination for CSHCN.

Investigator's Background and Assumptions

Understanding the background and identifying the assumptions of the investigator are important steps in qualitative research. As much as the investigator tries to remain neutral in the approach to data gathering and analysis, there is no way to completely divorce the experience and assumptions of the investigator from the design and results of the study. In particular, qualitative descriptive studies require the researcher to refrain from interpretation of the data in light of any previously accepted theory, framework or belief system. Identifying assumptions at the beginning of the research allows the investigator to be cognizant of biases and to control for those biases in the design and reporting of findings. Although not perfect, this step encourages the investigator to be vigilant in the development of the research design and is in the forefront of the mind of the investigator during data analysis.

The investigator had experience as a school nurse and worked directly with CSHCN. For seven years she was responsible for a high school of 2000+ students in a

suburban school district. Each school in the district was assigned only one licensed school nurse with one school nurse typically responsible for multiple elementary school buildings and one school nurse per larger middle or high school buildings. Within this school there were a number of CSHCN some of which had very rare medical conditions or were medically fragile.

The school nurse frequently works in isolation as the lone licensed school nurse in a school building or district. The investigator was intrigued as to how the school nurse could manage such a large population of students along with addressing the special healthcare needs for CSHCN with limited personnel, equipment, and time. The investigator was interested in capturing through a qualitative research study the factors which impact school nurses who attend to the work of care coordination for CSHCN.

The investigator designed this research on the foundation of two assumptions. The first assumption was that all children should achieve a level of education which represents their highest potential. Federal and state laws (Department of Education, 2006; Minnesota Office of the Revisor of Statutes, 2010) support the right of each child to have a free and appropriate education in the least restrictive environment. These laws do not speak to the quality or level of achievement expected. The desire to reach the highest potential whether physical or emotional is a standard practice for nursing. School nurses practice in the educational environment and therefore design interventions to maximize physical and emotional well-being with an ultimate goal of improving educational outcomes. Though a causal relationship between school nursing interventions and educational outcomes is unproven, it was an underlying assumption of

this investigator that school nursing interventions have a positive impact on educational success.

The second assumption was that the participants in the study would also desire for CSHCN to not only receive an appropriate education but receive an education that maximizes their potential. This belief might be evidenced through the information gathered during interviews regarding care coordination for CSHCN. In the issue brief from the National Association of School Nurses (NASN) on management of CSHCN by school nurses, the legal requirements are clearly stated and the rationale for requiring school nursing care is schools is reviewed (National Association of School Nurses, 2006b). This document does not present evidence to support the relationship between care coordination activities by school nursing and a positive impact on the educational outcomes of CSHCN. Therefore, without legal or scientific evidence to require or support nursing care coordination beyond that necessary to ensure the CSHCN attend school, school nurses must have some internal value or belief system which supports the school nurses' comprehensive efforts on behalf of CSHCN.

Significance

Estimates suggest 14.2 million school aged children have chronic medical conditions requiring medical care beyond that of the average child (Bethell et al., 2011). Amid this increase a decrease in funding and staffing can be found in many school districts. Reduced funding is a result of cuts in legislative spending and a downturn in the economy. The requirements of the federal laws have not changed and are not anticipated to change in response to economic pressures. Therefore school nurses must be able to do more with less.

The role of the school nurse has not changed; it continues to revolve around seven identified roles (National Association of School Nurses, 2009). One of the roles of school nurses is to serve as a liaison between the school, family, community and other healthcare providers. In this role, the school nurses utilizes the nursing systematic process to identify, gather information about, plan for and evaluate the healthcare needs of all students. During this process the school nurse reaches out to families, staff and other healthcare providers to partner in planning for the needs of the student. The school nurse also serves as the health expert in the educational planning during special education team meetings (National Association of School Nurses, 2009). During IEP development any medical needs of the student which might hinder educational success are identified. Those concerns are addressed and a plan is developed by the school nurse (National Association of School Nurses, 2008). This liaison role of the school nurse aligns well with the concept of care coordination.

The federal government has recently enacted healthcare reform measures to try to reduce spending. One of the measures identified is care coordination for individuals covered under federally sponsored healthcare programs through the Centers for Medicare and Medicaid Services (CMS) in a medical home or accountable care organization (U. S. Department of Health and Human Services, 2011). CSHCN utilize a far larger proportion of healthcare dollars than do their healthy counterparts (Weller, Minkovitz, & Anderson, 2003). Every effort to reduce healthcare spending is necessary for the government and for economic growth. A large percentage of CSHCN receive healthcare through some type of governmentally sponsored program (Bumbalo, Ustinich, Ramcharran, & Schwalberg, 2005). Efficient utilization of healthcare dollars has propelled the effort to

develop medical homes with care coordinators for CSHCN, to incite the insurance companies to employ case managers to try to cut unnecessary expenditures and for efforts on the part of public health systems to identify early those that need additional healthcare services to reduce negative long term outcomes. Little effort has been made to mobilize the skills and knowledge of the school nurse as a partner in this effort. The school nurse as the health expert in the educational system and with an identified role as a care coordinator could partner across systems, healthcare to educational, to plan for the needs of CSHCN. Identification of school nurses as significant partners in the effort to provide cost-effective, high quality of care to CSHCN would further support the role of the school nurse as care coordinator in the educational setting.

Recently the Robert Wood Johnson Foundation and the Institute of Medicine released a report called *The Future of Nursing: Leading Change, Advancing Health.* One recommendation for action contained in the report related to the expanded role of nursing in the healthcare system. A key message in that report was "nurses should practice to the full extent of their practice and training" (Institute of Medicine of the National Academies, 2011, para. 3). This current study contributes to the knowledge of how school nurses perceive their role as care coordinator and highlights the efforts of the school nurse to provide coordinated healthcare to CSHCN. Describing the factors which impact school nurses' ability to perform care coordination might provide insights on how to expand this role of care coordinator to other practicing nurses.

Chapter Summary

The face of the population of school children has dramatically changed over the past few decades and certainly since the early 1900's with the advent of school nursing.

School nurses increasing manage children with complex medical or emotional needs. Federal legislation has reintegrated CSHCN into the public school system ensuring a free and appropriate education for these special needs students. Accommodations in the educational setting, necessary for some students, might be the coordination of their healthcare conditions across multiple settings, home, hospital, clinic, community and school. Care coordination occurs in multiple systems as well. Each system has designated individuals who might be involved in care coordination.

Care coordination occurs in the healthcare, educational, public health systems along with the insurance industry. Within the school setting the school nurse is responsible for the healthcare and coordination of healthcare for all students. CSHCN because of their complexity of healthcare needs present a special challenge to the school nurse. Limited time, resources and communication across systems often leave the school nurse to manage and coordinate care in a state of isolation. Describing the factors which impact school nursing efforts of care coordination for CSHCN is a first step to support and possibly expand school nurses' role in care coordination. The school nurse has an impact that stretches across location and time; the unsung hero of the healthcare and educational systems.

CHAPTER 2 LITERATURE REVIEW

There is scant research addressing school nursing care coordination for CSHCN. There is however a large body of literature concerning care coordination for CSHCN and separately school nursing outcomes. In this chapter a review of the literature related to these areas will be presented. A conceptual framework was selected to guide the design of the semi-structured interview questions. A review of the literature related to the framework is also presented.

Search Strategies

CINAHL, PubMed and Google Scholar databases were searched using the key words of care coordination, children with special healthcare needs, and school nursing. These terms were first searched individually and then in combination to provide the final list of articles for potential review.

This investigator reviewed literature related to care coordination in the healthcare and education systems. Abstracts of articles were reviewed as the first step in selecting those to include in this literature review. Reference lists of the selected journal articles were searched for additional references. An automatic alert for all literature related to children with special healthcare needs was devised through PubMed. This allowed the investigator to remain current on emerging literature related to CSCHN throughout the dissertation process.

Topics Addressed in Literature Review

The following section represents a review and critical analysis of the literature related to the following topics:

- Care coordination for children with special healthcare needs with a focus on care coordination in the healthcare and educational systems.
- School nursing outcomes research for children with special healthcare needs.
- A conceptual framework for school nursing practice.

Care coordination.

Care coordination has been identified as one of the top 20 national health priorities by the Institute of Medicine (*Priority areas for national action: Transforming health care quality*, 2003). CSHCN might receive care coordination services in a variety of systems. The systems in which the CSHCN might interact and receive care coordination services are: the educational system, the public health system, the insurance system and the healthcare system. The focus of these systems varies according to the priorities of the system. The educational system focuses on providing the most appropriate education in the least restrictive environment. The public health system focuses of the health of the population at large and providing services to at risk groups. The insurance system focuses on reducing the economic impact of high cost services. The healthcare system focuses on producing optimal health for all who have access. For the purposes of this review the focus will be on the healthcare system and the educational system.

For the purposes of this research, the review of the care coordination literature will focus on: 1) ambulatory pediatric care coordination for CSHCN especially in the medical home model, 2) impact of care coordination for CSHCN, 3) providers of care coordination in the healthcare system, and 4) care coordination for CSHCN in the educational system. This review will seek to clarify care coordination and will also describe some of the activities which are considered part of care coordination. Additionally, the barriers to care coordination will be identified along with the sources of care coordination activities for families and CSHCN.

Care coordination in ambulatory pediatrics.

CSHCN represent a significant number of children in an ambulatory pediatric practice. In a recent National Survey of Children with Special Health Care Needs conducted in 2001, the prevalence of CSHCN was 12.8% (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2004) of which 52.6% reported access to a medical home in a pediatric setting. A medical home model is said to contain five essential components: 1) the medical home is the usual source of care for the patient, 2) the patient has an indentified personal doctor or nurse, 3) the medical home personnel facilitate access to specialty care, 4) care coordination services are provided, 5) all in a family centered healthcare environment (Strickland et al., 2004).

Not all pediatric medical home practices are able to provide all five essential components for all enrolled CSHCN. In particular, care coordination activities have been found to be frequently lacking in many medical homes. Care coordination is not just a single activity performed on a one time basis in a clinic. Care coordination in the

healthcare system may involve any of these activities: “planning treatment strategies; monitoring outcomes and resource use; coordinating visits with subspecialists; organizing care to avoid duplication of diagnostic tests and service; sharing information among health care professionals, other program personnel, and family; facilitating access to services; planning a hospital discharge; and notification, advanced planning, training of caregivers, education of local emergency medical services when a CSHCN lives in their community and finally ongoing reassessment and refinement of the care plan” (Committee on Children with Disabilities, 1999, p. 979).

One of the challenges is the proportionally larger amount of care coordination time that CSHCN require. It was noted that 14% of the CSHCN who had psychosocial problems consumed 21% of the care coordination minutes but 50% without psychosocial problems only required 36% of the care coordination minutes (Antonelli, Stille, & Antonelli, 2008). Each minute of care coordination time costs on average of $7.78 with a range of $4.39 to $12.86 depending on the type of personnel providing the service (Antonelli, Stille, & Antonelli, 2008). This is a hefty expense for a practice when care coordination activities currently are not reimbursable by insurance companies.

In one study by Kastner & Walsh (1999), health care providers and other personnel spent 44% of their time on non-billable services for CSHCN. Hiring individuals to take over this burden resulted in a return on investment of over 10 to 1 (Kastner & Walsh, 1999). The annual cost of care coordination to the medical home model ranged from $22, 809 to $33, 048 (Antonelli & Antonelli, 2004). Understanding the cost to the individual practice versus the potential benefits has continued to lag behind actual efforts to provide consistent care coordination in many practices.

Increased utilization of care coordination time reflected severity of condition, lack of insurance coverage, need for ancillary services and inadequate communication between providers (Bumbalo et al., 2005; Rosenberg et al., 2005). One study found the most complex CSHCN constituted 11% of the population but they utilized 25% of the care coordination encounters and took 4 times longer than the less complicated CSHCN (Antonelli & Antonelli, 2004). When comparing care coordination to service utilization for CSHCN versus children with undiagnosed developmental delays (UDD), findings support an increased need for care coordination among CSHCN (Nolan, Young, Hebert, & Wilding, 2005). There is evidence to support the increased need for care coordination among CSHCN.

Impact of care coordination.

Care coordination has demonstrated some beneficial outcomes for the patient, family and the healthcare system. One program through Shriner's hospital reported 36% of the parents of CSHCN interviewed felt their child was able to function better and 29% reported fewer complications as a result of care coordination services (Presler, 1998). These were not the only improved outcomes demonstrated by this group. There were additional impacts on the family and the healthcare system.

Family impacts included ease of access to medical supplies and equipment (49%), better understanding of agencies and services (48%), less worry and time spent on obtaining healthcare for their child (41%) and more help was available (45%) (Presler, 1998). Reducing the economic impact on families was also reported such as decreased odds of spending more than $500 per year out of pocket expenses, spending more than 4 hours per week on care coordination activities and stopping or reducing work hours

(Turchi et al., 2009). Parents who have adequate knowledge of the health concerns of their child are expected to lead the care coordination team. When they are unable to perform this duty, the medical community assumes that role (Ziring et al., 1999). Parents or families leading care coordination efforts might benefit from school nursing support this continuing effort to navigate systems which at a minimum are confusing and can be outright daunting to the unfamiliar.

The healthcare system has also seen benefits from care coordination in relationship to reductions of emergency room visits, hospitalizations or unplanned office visits (Antonelli et al., 2008; Klitzner, Rabbitt, & Chang, 2010; Presler, 1998). Presler (1998) found among 1094 subjects 22% reported fewer hospitalizations, 43% reported fewer trips to the doctor and 35% more reported community based therapy and other services. Decreased utilization of high cost portions of the healthcare system can drive down the overall financial burden to the community and the nation as many of the CSHCN receive their care as a part of federally or state funded health insurance programs (Bumbalo et al., 2005). Conversely when care is not coordinated in a consistent manner the potential for overutilization and waste might be realized.

Families of 40,723 CSHCN were surveyed regarding the existence and adequacy of care coordination for their children. Families reported receiving care coordination in 68.2% of instances but only 59.2% of these same families judged the care coordination to be adequate (Turchi et al., 2009). Mathematically, this represents only 40.3% of all surveyed families believe they received adequate care coordination to meet the needs of their child. If one of the standards of a medical home model is to provide care coordination then less than half of the time is this actually happening. Barriers within the

healthcare system must exist that prevent the provision of care coordination. Research has identified some of those barriers. Those barriers generally revolve around the question of who is responsible for providing the care coordination.

Providers of care coordination.

Most of the 803 surveyed pediatricians (71.2%) reported that they or someone in their practice provided care coordination to CSHCN (Gupta, O'Connor, & Quezada-Gomez, 2004). These pediatricians who were members of the American Pediatrics Associations were specifically asked about six care coordination activities. These activities included: 1) integrating all care plans across providers, 2) discuss non-medical needs of the family, 3) additional time at clinic visits for CSHCN, 4) contacting schools regarding educational needs, 5) hospital discharge planning, 6) appointments scheduled to discuss results of specialist visits. The range of response for always performs these named activities was 18.8% to 49.1% of the time. The major barriers cited for not performing these functions were limited time and lack of medical staff in the clinic (Gupta, O'Connor, & Quezada-Gomez, 2004). It has been demonstrated that investing in care coordination is cost effective though all pediatricians are not providing all care coordination activities.

The question then arises as to whom might perform care coordination if pediatricians are unable due to concern for compensation and lack of time or personnel. In a number of instances, nurses were mentioned as individuals likely to provide care coordination for CSHCN. Clinic nurses provided care coordination which resulted in positive feedback from families (Wood et al., 2009). In other instances nurse practitioners have been cited as reasonable selection to lead care coordination efforts (Farmer, Clark,

Sherman, Marien, & Selva, 2005; Lindeke et al., 2002; National Association of School Nurses, 2005). In the public health area social workers, nurses or trained personnel called key workers are employed as care coordinators (Appleton et al., 1997; Cundall, 2001). The selection of the most appropriate person for the role of care coordination might be based on the needs of the family.

Care coordination can be initiated in multiple systems, the healthcare, educational, public health and insurance. Care coordination in the ambulatory healthcare system has been described. Potential candidates for the role of care coordinator have been identified. Advanced practice registered nurses (APRN) were utilized in rural primary care practices as care coordinators. There were significant positive results after experiencing an intervention designed to improve care coordination. Parents were more satisfied with access to mental health services and care coordination in general (Farmer et al., 2005). Decreases in family needs, strain on caregivers, lost work days, school absences, and access of ambulatory services were noted (Farmer et al., 2005). The families whose children had more complex needs were more likely to report these decreases in needs (Farmer et al., 2005). Lindeke, Leonard, Presler and Garwick (2002) present an argument supporting pediatric nurse practitioners (PNP) as ideally positioned to serve as care coordinators. Their argument is based on the philosophy of family-centered care which is present within the care model espoused by PNPs and the ability of the PNP to act as a change agent to diffuse the family-centered care model to other care providers (Lindeke et al., 2002). Utilization of nurse practitioners might continue to present an economic disincentive for many pediatric practices. It has been noted before that the cost of care coordination is directly correlated with the individual salary costs of

the person providing the service (Antonelli, Stille, & Antonelli, 2008). Registered nurses have been recognized providers of care coordination (Kruger, 2004) and might serve as a cost effective care coordination resource in the primary care arena.

Registered nurses (RN) might also fulfill the role of care coordinators in the public health arena. The state of Tennessee developed a program for care coordination focusing on CSHCN. In this program RNs and social workers employed by local health departments were responsible for care coordination services (Cundall, 2001). Registered nurses were very successful in reducing costly services when providing care coordination in primary care. In 62% of the care coordination encounters by RNs there was an 81% reduction in emergency room visits and a 63% reduction in office visits (Antonelli et al., 2008). Another study by Wood et al (2009) compared care coordination by RNs in a practice site versus an agency based care coordination found a number of positive outcomes. Families of CSHCN reported improved care coordination experience, decreased barriers to services, improved experience with care coordinators, and a sense of being treated better by hospital staff (Wood et al., 2009). Registered nurses are a less costly alternative to APRN or physicians as care coordinators and they have demonstrated themselves capable of performing the duties of a care coordinator.

Other individuals can serve the role of care coordinators. In England the term key worker is used for care coordinators. These key workers are assigned to families of children with disabilities. The key worker is defined as “a named person whom the family can approach for advice about, and practical help with, any problem related to the disabled child” (Greco & Sloper, 2004, p. 13). Advantages similar to those previously noted for APRN and RN care coordinators have been noted. One concern raised by the

authors was the discovery that less than one third of families had an established care coordinator (Greco & Sloper, 2004). This was due in large part to the difficulties of working across agencies and commitment to the concept of care coordination within the agencies. One important finding was that families were best served when matched to a key worker based on their personal preference, geographical location, case load, skills of the key worker, and proper allocation by a local team manager (Greco & Sloper, 2004). The key workers receive specific training to perform the function of care coordination and have proved to be successful (Greco & Sloper, 2004). Care coordination activities can be performed by a variety of healthcare personnel. Whether physician, nurse, social worker, or key worker, the care coordinator needs to work with families to access the services necessary to benefit their children. The type of personnel providing the care coordination services might depend on the system where services are being accessed. In addition to the healthcare system, insurance, public health and educational systems are a source of care coordination. Within the educational system the RN, school nurse, assumes the role of care coordinator.

Care Coordination in the Educational System

Because CSHCN spend ample time in schools, it is imperative to coordinate care between the healthcare and educational systems. Contact between these systems has been found to be lacking. Multiple studies cited variable rates of contact from the healthcare to the educational system (Davidson, Silva, Sofis, Ganz, & Palfrey, 2002; Gupta et al., 2004; Nolan et al., 2005). Pediatricians reported an ability to coordinate school health services in only 15% of instances for CSHCN (Davidson, Silva, Sofis, Ganz, & Palfrey, 2002). Approximately twenty-three percent of pediatricians surveyed

reported they always contact schools regarding the healthcare and educational needs of CSHCN in their care (Gupta et al., 2004). Care coordinators for CSHCN reported that less than 5% of pediatricians provided input during the development of Individualized Family Service Plans (IFSP) for children under the age of three (Nolan et al., 2005). The IFSP document is a result of input from members of the school staff, parents and the child. School nurses are members of special education teams for CSHCN as they are most familiar with the healthcare needs of the students under their care. School nurses might review or access medical records to fully understand the medical care needed by CSHCN under their care. The school nurse might benefit from direct contact with care providers to improve that understanding.

Once the child with special healthcare needs is in the school system, primary care providers as part of their care coordination activities should be contacting school health services who care for CSHCN enrolled in the medical home (Gupta et al., 2004; Kruger, 2004). Eighty-three families who attended a clinic for children with physical disabilities were surveyed (Nolan, Orlando, & Liptak, 2007). Half of the families believed their provider never (24%) or rarely (26%) contacted the school regarding their child, though they ranked contacting the school as third in importance to the care of their child (Nolan, Orlando, & Liptak, 2007). The authors recommended that a clear method for communication between the healthcare and educational systems be established in response to the desires of families and needs of the CSHCN (Nolan, Orlando, & Liptak, 2007). Pediatricians surveyed by Gupta et al (2004) responded that only 23.3% of the time they contacted schools about CSHCN in the educational setting. Rural pediatricians reported communication to the school at a rate of 40.8% whereas in inner cities (25.8%),

urban (20.3%), and suburban (19.3%) rates were lower (Gupta et al., 2004). Thirty primary care physicians responded in a survey that they were dissatisfied with their ability to assist with care coordination in the school setting (Davidson et al., 2002). Communication between school and provider is essential if the CSHCN is to receive the most appropriate care in the school environment. If the provider is unable to initiate the contact with the school or parents are unable to manage all the care coordination needs of their CSHCN, then the school health service personnel will need to make the initial contact and begin the care coordination process.(Gupta et al., 2004; Kruger, 2004)

Within the educational system the likely candidate as the leader of care coordinator is the school nurse. The school nurse is often the solely responsible healthcare person for students and school personnel. Within the School Nursing Scope & Standards, care coordination is a function of the school nurse. In particular the school nurse documents the coordination of care and prepares and implements an individualized healthcare plan for CSHCN (National Association of School Nurses, 2005). The school nurse clearly leads the coordination of care within the educational system but prior to the age of three; the educational system may be leading care coordination across both the school and the healthcare system. In this instance care coordination takes the form of an Individualized Family Service Plan (IFSP) for children under the age of three and then over the age of three, an Individualized Education Plan (IEP) (Lindeke et al., 2002). Following age three the complexity of healthcare needs shifts the burden of care coordination primarily to the healthcare system. The schools begin to focus primarily on the educational needs of the child and healthcare coordination can vary widely from district to district depending on availability of school nursing care.

The first reference to care planning for CSHCN in schools appears in an article by Dunn (1984). This time frame coincides with the move to integration of CSHCN into the public school system. More school districts were mainstreaming students with disabilities, moving from specialized schools to local community schools. Dunn (1984) advocated for the documentation of the nursing process for handicapped students (Dunn, 1984). Today a handicapped student would be referred to as a CSHCN but the concept of written care plans still persists in the form of an IFSP, IHP or emergency care plan (ECP).

The school nurses scope and standards of practice identifies two standards for care coordination for the school nurse. The school nurse creates and implements IHPs and the school nurse documents coordination of care activities (National Association of School Nurses, 2005). The National Association of School Nurses defines the care coordination activities of the school nurse in the Role of the School Nurse document. Specifically it states: “The school nurse serves as a liaison between school personnel, family, community and healthcare providers” (National Association of School Nurses, 2009, para. 10). School nurses demonstrate this role through communication with family, community healthcare providers and community healthcare agencies, representation of the school within the community and development of partnerships in the community to promote the health of the community (National Association of School Nurses, 2009). The function of a care coordinator is consistent with the role of the school nurse as described.

Within an educational system, the care coordination activities vary somewhat. They might include activities such as identifying individuals needing testing for special

education, therapy or nursing care, creating and updating individualized care plans for families and students, acquiring adaptive equipment for the student to use in school or arranging for special transportation to and from school or within the school building (Committee on Children with Disabilities, 1999). The activities in the school are focused on creating an environment where the student will have optimal educational success while maintaining optimal health. The Committee on Children with Disabilities (1999) did not address coordinating care outside the walls of the school building.

It has been demonstrated that care coordination can occur within and across multiple systems. There is lacking a clear method of communication across systems especially between the healthcare and the educational systems (Davidson, Silva, Sofis, Ganz, & Palfrey, 2002; Gupta et al., 2004; Nolan et al., 2005). Even though communication from the pediatric medical home to the school is an expectation, this occurs in less than one third of all instances for CSHCN (Gupta et al., 2004). Given these limitations, much of the care coordination responsibility for CSHCN in the educational system will fall to the school nurse. Research is lacking which describes how school nurses perceive or carry out care coordination activities in the schools. Some information is available to describe school nursing outcomes based on care planning but there is nothing from the point of view of the school nurse to help describe the methods they employ or the factors which impact their ability to perform care coordination functions.

School Nursing Outcomes Research

School nursing services encompasses meeting the health needs of groups of students, the individual student and staff members within a school building. Nurses providing these services are becoming more accountable for the outcomes of their service

to parents, principals, and politicians in order to support the need for continuing or increasing nursing services to school-aged children. Stock, et al (2002) reviewed 15 studies identifying outcomes of school nursing service. These outcomes were a result of specific research interventions such as asthma education programs, quit smoking education, obesity interventions, violence prevention, and immunizations. Eleven of the studies had an intervention and a comparison or control group. In all instances the intervention group scored higher on the evaluation metrics than did the control or comparison group. These studies support the concept that school nursing services have a positive impact on the students. The authors recommend the development of a nursing minimum data set for school nursing services in order to more comprehensively capture and compare outcomes across populations and settings (Stock, Larter, Kieckehefer, Thronson, & Maire, 2002).

The impact of school nursing interventions was identified early on in the history of school nursing. A recent evaluation of the outcomes of school nursing was summarized in the work of Maughan (2003). Fifteen school nursing interventional studies from 1965 – 2002 were reviewed. These studies were reviewed with an eye to the impact on school performance. Absenteeism is felt to negatively impact school performance because of the decreased amount of in-class time (Maughan, 2003). Identified in the review were interventions to reduce absenteeism which took the form of phone calls to parents, hand washing classes, full time school nurse in elementary school buildings and individualized interventions targeted to students with high absenteeism rates. All of these interventions demonstrated a positive impact on reducing absenteeism (Maughan, 2003).

The second group of interventions Maughan (2003) identified was targeted toward particular student populations. Those particular populations included students with chronic illnesses, developmental delays, and high risk behaviors like teen pregnancy, alcohol consumption, and smoking. Although the school nurse interventions in these studies were not found to have a relationship to absenteeism, positive outcomes like reduced anxiety with an asthma attack, ability to perform relaxation techniques for chronic headaches resulting in a decrease in the numbers of headaches and improved coping skills for depressed students was found. School districts with lower student-school nurse ratios had fewer teen pregnancies, fewer violent deaths, and higher school graduation rates (Maughan, 2003). Some school nurse interventions are directed toward family members with the hope of improving student outcomes through the partnering with families.

School nurses have partnered with parents to improve outcomes for students and some interventions in this review were directed toward parents. Personal support for parents of children with asthma, and improved immunization rates resulted from direct contact between the school nurse and the parents. A parent outreach program resulted in improved health survey return rates, increased immunization rates and increased rates of parent initiated contact with the school nurse. A variety of positive outcomes were identified from school nursing interventions targeted to improve the health of particular students or to improve attendance in targeted populations of students. These 15 studies had no consistent measurement across the groups, absenteeism measurement varied from study to study and some of the other positive outcomes were measured in a qualitative manner (Maughan, 2003). This review identified a wide variety of positive outcomes of

school nursing without presenting outcomes measured in a similar manner across locations. It is important to develop guidelines by which measures are consistently defined and collected in order to verify that school nursing has positive impact on student outcomes in a variety of circumstances and locations.

Using a focus group technique Selekman and Guilday (2003) assisted school nurses leaders to identify 10 important outcomes of school nursing care. These outcomes are 1) increased student in-class time, 2) receipt of appropriate first aid and health care, 3) receipt of competent health interventions, 4) meeting the comprehensive needs of CSHCN, 5) disease prevention and wellness programming to increase overall school health, 6) appropriate referrals for identified problems, 7) the school is a safe environment, 8) community outreach efforts result in enhanced school health, 9) cost effective school nursing services, and 10) student, staff and parent satisfaction with school nursing services. In addition to these ten outcomes, the groups were asked to identify the specific quality indicators that could be used to measure the identified outcomes (Selekman & Guilday, 2003). With this information in hand, researchers focusing on school nursing can begin to coordinate efforts to measure and compare outcomes related to particular interventions. Those interventions with better outcomes might provide support for other school nurses wishing to implement interventions to improve student outcomes in their schools or districts.

A number of successful school nursing interventions have been targeted toward children with asthma. Asthma is the most common chronic condition of childhood (Centers for Disease Control and Prevention, 2009). In one study (Taras, Wright, Brennan, Campana, & Lofgren, 2004) over three years time students with asthma were

identified and school nurses tracked the types of case management activities the student received: home visit, contact with a parent, contact with a provider, or asthma education. There were significant differences discovered for students receiving even one case management activity. Those students had increased likelihood of available medications at school, increased likelihood of using a peak flow meter at school, decrease in overall absenteeism for illness and a change in asthma severity rating from one year to the next (Taras, Wright, Brennan, Campana, & Lofgren, 2004). This study was a retrospective study which did not require the school nurse to purposely seek out students for case management activities or to randomly select students for comparison. In this study and a number of studies to follow, the term case management is utilized by the authors. Case management and care coordination are often used interchangeably. For the purposes of this review they will be considered synonymous.

In one study (Levy, Heffner, Stewart, & Beeman, 2006), 14 schools in the Memphis City Schools were randomized to a case management intervention group or to a control group. At the end of the intervention these two groups were compared. The intervention involved nurses meeting weekly from October to May with students identified as having asthma. The meetings focused on asthma knowledge and treatment techniques. The findings were significant for a reduction in absenteeism, fewer urgent care or emergency room visits, fewer hospital days, and improvement in asthma knowledge by students participating in case management meetings (Levy, Heffner, Stewart, & Beeman, 2006). The students who participated in the case management intervention were self selected and did not represent a targeted sample based on the severity of their disease. Challenges identified in the study related to providing case

management with a medical focus in an educational setting though when improvements in the health status of the children became clear to administrators and staff, the case management nurses found increased support for the intervention. The school district wanted a more public health research approach so the entire population of children with asthma was eligible for inclusion in the intervention group. This is a costly approach and the question of sustainability needs to be addressed. Weekly visits with up to 7% of your student population (the prevalence of asthma in children according to the CDC (Centers for Disease Control and Prevention, 2009)) could be a tremendous demand on a school nurses time and sustainability of such an approach could be questionable. One way to maintain costly programs is to provide evidence that the intervention resulted in a reduction of healthcare expenditures, essentially paying for it.

One school nurse led intervention reported by Byrne, Schreiber, & Nguyen (2006), partnered with a healthcare organization demonstrated an overall reduction in healthcare costs. In New York State children are allowed to carry metered dose inhalers (MDI) while in school which can be a helpful situation for nurses; students can manage mild asthma symptoms in the classroom without having to go to the nurse's office. On the other hand it can also lead to unexpected complications that the nurse has to handle should the child not have the MDI available at school, either forgotten at home or did not refill the inhaler when the doses were complete. In those instances the school nurse is faced with few options for treatment beyond calling the parent or calling emergency services to take the child to the local emergency department. Partnering with a healthcare organization, school nurses received nebulizer equipment and medications to have on hand to treat cases of asthma. As a result of the case management activities and

availability of nebulizer treatments children spent more time in the classroom, nurses felt more comfortable managing asthma episodes, parents felt more at ease, there were fewer emergency department and unscheduled office visits and a decreased need for ambulance service. These outcomes translated to an overall reduction in healthcare expenses for treatment of these children with asthma (Byrne, Schreiber, & Nguyen, 2006). Partnering with the family and the community along with case management activities can improve outcomes as long as the nurse has the necessary authorization for treatment or guidelines from the healthcare provider responsible for the medical management of the child.

Any medical treatment, beyond basic first aid, requires written authorization for treatment by the primary care provider (PCP) and approved by the parent. One form of authorization for children with asthma is called an Asthma Action Plan (AAP). This plan includes names, dose, instructions for medication administration, individualized interventions based on peak flow meter readings, and is signed by both parent and PCP. An evaluation of the availability and use of AAP was performed in Hartford, Connecticut. The findings of a study by McLaughlin et al (2006) suggest that when an AAP is available, the school nurse will refer to that plan up to 93% of the time when treating a child with an asthma episode. The overall availability of an AAP at the time of an asthma episode was at most 26.6% for the treating school nurse. School nurses reported that obtaining AAP from the PCP was not an easy process but that having the contact information for the PCP was useful when treating students in the school setting (McLaughlin et al., 2006). The AAP like the IHP has goals, interventions and outcomes identified for the child with asthma though the IHP has no requirement for sign off by the PCP or parent. The AAP is individualized for each child and is useful to the nurse in the

management of the child during an asthma episode. There are other chronic conditions beside asthma that a school nurse must manage. A model for chronic condition care including chronic disease management and coordinated school health care has been proposed by Erickson, Splett, Mullett and Heiman (2006) to assist the school nurse in planning and carrying out individualized care for CSHCN.

A model called the Healthy Learner Model was proposed to assist the school nurse link care in the school to healthcare providers and families (Erickson, Splett, Mullett, & Heiman, 2006). This model was implemented in a program called the Healthy Learner Asthma Initiative (HLAI). There are seven elements and two requisites to the model. In planning the HLAI, the elements and requisites were evaluated for outcomes as an essential part of the initiative (Erickson, Splett, Mullett, Jensen, & Belseth, 2006).

The first element, leadership, was represented by an Asthma Team which not only developed and implemented the HLAI but also was responsible for modifying the initiative based on feedback and establishing a methodology for sustainability of the initiative. Evidence based practice guidelines for the HLAI were developed and represent the second required element of the model. The review of evidence was performed by work groups with representation from school districts, healthcare facilities, families and public health and community organizations. As more evidence became available, the guidelines were modified to reflect current best evidence for practice (Erickson, Splett, Mullett, Jensen et al., 2006).

In order for the evidence based guidelines to be adopted into practice, education and skills development (capacity building) was necessary. Capacity building is the third element and was evaluated by observation and surveys to assess nurses' knowledge of

asthma. Additionally, sufficient equipment in the form of peak flow meters, spacers, nebulizer equipment and metered dose inhaler trainers were provided to ensure the nurses' capability of providing care and teaching to students with asthma. An Asthma Resource Nurse (ARN) was employed by the school district. The ARN was the fourth element in the model. The ARN served as a resource to schools and school nurses and as a liaison between the school district and healthcare providers, community agencies and state and local asthma committees. When surveyed staff reported that the ARN support was the most valuable part of the training they received (Erickson, Splett, Mullett, Jensen et al., 2006).

The fifth element, healthy learner, is centered on the student. Asthma interventions were individualized by obtaining AAP from providers and completion of asthma questionnaires by parents or older students. The data gathered from these sources allowed the nurse to develop an individualized plan for care which included education and teaching self-management skills. The result for those students who received case management care was an overall reduction in the numbers of visits to the school health office and an apparent positive impact on school attendance. Elements six and seven were focused on partnerships with parents and healthcare providers. Families participated in surveys and focus groups to help understand the impact that asthma has on the student's quality of life. Healthcare providers had input into the development of a revised AAP which could serve as a medication order, authorization for treatment and an authorization for exchange of information between the school nurse and the healthcare provider. The outcome of the development of the modified AAP was reduced amount of

paperwork both for the nurse and the healthcare provider and increased communication between the two (Erickson, Splett, Mullett, Jensen et al., 2006).

The requisites to the model were professional school nursing and evaluation. School nurses are experts and advocates for student health and they are integral to the partnerships between parents and healthcare providers. The other requisite is evaluation. Evaluation was an ongoing process that begins at the development and proceeds through implementation and sustained management of the HLAI. Evaluation of the project over five years helped secure additional funding and assured that the limited resources available to continue the project were judiciously distributed (Erickson, Splett, Mullett, Jensen et al., 2006). The HLAI has demonstrated that professional school nursing practice impacted the outcomes for students with asthma given the support of the ARN and the Healthy Learner Model. Other students also benefit from targeted interventions by professional school nurses.

One approach to help utilize school nursing resources to the maximum is to identify which students might most benefit from school nursing care coordination. This approach consists of targeting those students who demonstrate excessive absenteeism due to illness. One study evaluated nursing interventions and impact on excessive absenteeism (Weismuller, Grasska, Alexander, White, & Kramer, 2007). In this study 17% of elementary students were absent due to illness 11 or more days. It was discovered that school nurses did not receive referrals for students with high absenteeism due to illness. In this retrospective records review, school nursing initiated interventions were not found to impact excessive absenteeism. This result may have been due to the discovery that the majority of school nursing interventions did not target absenteeism but

targeted management of health conditions and school nurses did not seek out students with high absenteeism for interventions. The students sought out for interventions by the school nurses were students with previously known chronic conditions (Weismuller, Grasska, Alexander, White, & Kramer, 2007). In this instance attendance as an outcome measure did not appear to be impacted by nursing interventions. These findings present an opportunity for reflection on school nurses' ability to impact attendance if more referrals for excessive absences would be made or if school nurses could develop interventions specifically aimed at student with high absenteeism.

In one large urban school district an initiative targeted specific students who were at risk for poor school performance. These students were enrolled in a school nursing case management program. Students who met the criteria for case management included those: 1) with whom the nurse had multiple encounters, 2) who have academic concerns possibly related to illness, 3) who have poorly controlled chronic conditions, 4) who have behavioral or health issues that interfere with learning and 6) students with excessive absenteeism. The results of the case management activities were evaluated for each individual student against five predetermined outcomes (Bonaiuto, 2007).

The five outcomes were: absenteeism, academic success, problem behaviors, disciplinary action, health or health compliance and quality of life as reported by student or parent report. In 84% of the students at least one of the five outcomes demonstrated improvement. Taking each of the outcomes individually, quality of life was the criteria where most improvement was demonstrated, 59% of students reported improvement and 67% of parents or teachers reported a noticeable improvement, followed closely by 63% reporting improvement in health or health compliance. The remaining three outcomes

reported improved attendance in 34% of students, improved grades in 29% of students and behavior improved in 27% of students. Initially nurses were able to manage only 4.4 students per nurse but as the project carried on into further years the nurses became more familiar and more efficient in the provision of case management finally serving about 10 students per nurse in case management activities (Bonaiuto, 2007). This study did not use a standardized measure of quality of life (QOL). The student or parent qualitatively reported a change in QOL throughout the study. Stronger support for this finding would require the use of a standard measure such as the PedsQL tool. Other researchers have used standardized QOL tools and have replicated the findings of this study.

Nurses in one study enrolled students with asthma, diabetes, seizures, sickle cell disease or severe allergies to participate in case management activities (Engelke, Guttu, & Swanson, 2008). The students selected were also having difficulty managing their illness at school and were struggling academically. The evaluation criteria selected were absenteeism, change in grades, and QOL scores. QOL measurements were made with three versions of the PedsQL tool, one version specifically for asthma and one version designed for diabetes and finally a generic version. The nurses developed individual goals, interventions and outcomes. One intervention for all the students with chronic illness was to develop an IHP and an ECP. At the end of the year it was found that attendance was a poor measure with some students improving and some worsening attendance. Grades improved most for the lowest performing students, with 60% of the students with D/F grades improving. For children with asthma there was a significant improvement in overall QOL and in a subscale representing treatment and symptom control. For children with diabetes a significant improvement in overall QOL and in

barriers to treatment subscale were noted. No significant changes in QOL were noted for children with seizures, sickle cell disease or severe allergies. This may be due to the relatively small numbers of students in these groups. Together they represented only 14.5% of the total study group (17 of 114 students) (Engelke, Guttu, & Swanson, 2008). It has been demonstrated twice that QOL was impacted by case management activities performed by school nurses. It is hard to attribute improvement in grades to activities of the nurse because often those students with the poorest performance from previous school years are targeted by educational staff for additional educational activities targeted to improve academic performance. Some of the improvement in students' educational performance and management of their disease might best be captured in qualitative reports from parents, teachers or students.

Using data from the same study, the previous authors reported qualitative data describing positive outcomes from school nursing case management. Two examples of improvement which were not captured in the quantitative data collection techniques suggest two students with diabetes experienced improvement in control of their disease and the parents reported feeling supported by the school nurse, allowing the student to see herself as "just a kid and not a problem in the classroom" (Engelke, Guttu, & Warren, 2009, p. 424). Like the Healthy Learner Model previously discussed, the model presented in this research relied on capacity building of the nursing staff. The capacity building activities provided knowledge, skills and support for nurses to become effective case managers (Engelke et al., 2009). The qualitative results may not have been a result of the case management capacity building provided to the nurses but the standard of care that

school nurses provide to all students with chronic conditions that are not well controlled or newly diagnosed.

School nurses have the capacity to develop interventions for individual students or groups of students. The interventions where case management has been a focus resulted in improvement of the disease process and management of symptoms, improved quality of life scores and improved educational outcomes such as grades and attendance. School nurses have a long tradition of providing healthcare for CSHCN in the school system, have established an expectation of care coordination for CSHCN, and have an established history of positive outcomes for CSHCN resulting from school nursing interventions.

Conceptual Framework

The overall purpose of this study was to explore the factors which impact school nursing care coordination for CSHCN. The conceptual framework for school nursing practice (Wold & Dagg, 1978) assisted the researcher in formulating questions for inclusion in the interview guide to reflect the purpose of the study. This framework depicts the five concepts which are the basis for school nursing practice. The five concepts incorporated in the model are public health, adaptation, systematic process, tools and helping relationships. A copy of the model can be found in figure 1.

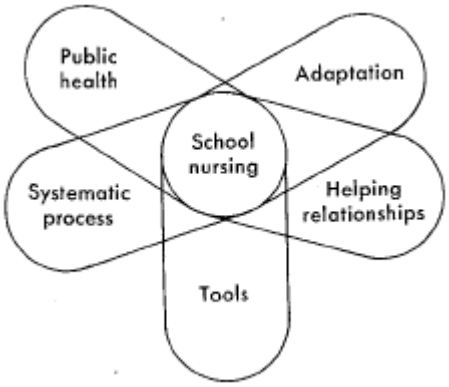

Figure 1: Conceptual framework model for school nursing reproduced from S. Wold & N. Dagg, 1981, School Nursing: A Framework for Practice, p. 31. Copyright 1981 by C. V. Mosby Company. Reprinted with permission.

The concept of public health anchors school nursing within the community, not just within a school building. School nurses address the three levels of public health; primary, secondary and tertiary prevention. The primary level includes health promotion and prevention of illness. Examples of this level would be school nurses teaching students hand washing techniques to prevent spread of illness or a "Cover Your Cough" campaign to prevent the spread of flu during the winter months. The secondary level reflects early diagnosis and treatment of illnesses for the purpose of limiting potential disability. An example of this would be a school nurse recognizing the signs and symptoms of illnesses which present in the health office such as fever and sore throat which might be a viral illness, strep throat or mononucleosis. Advising parents on next steps for treatment or evaluation can limit the number of days the student misses school and reduces cross infection to family, other students and within the community. The tertiary level focuses on rehabilitation. An example of a tertiary level activity is care coordination for CSHCN. Care coordination for CSHCN has a focus on rehabilitation

along with primary and secondary prevention. Much of the effort on the part of school nurses is focused on maintaining or improving the health status of CSHCN over many school years which represents a rehabilitative focus of care (Wold & Dagg, 2001). School nurses seek to maximize the health potential of the students, school and community where they practice based on the principles of public health.

The concept of adaptation represents the adjustments which an individual makes to changes in either the internal or external environment. School nurses assess adaptation of their clients who are students by observing and evaluating behaviors exhibited. The goal for the school nurse is to assist clients to adapt in a positive manner to the changes in their environment. School nurses seek to support clients to achieve their potential; both health potential and educational potential. An example of adaptation would be a student with a recent leg fracture returns to school using crutches for mobility. The school nurse recognizes that the student will be less mobile than before and more at risk for a fall with potential harm. The school nurse evaluates the student's proficiency with crutches and adapts the student schedule to allow more time to pass in the halls while learning to use crutches. Once the student is either proficient on crutches or weight bearing on the leg, then the regular schedule can be reinstated and the student can return to regular activities (Wold & Dagg, 2001).

Systematic process is a methodical approach to evaluating and planning care for clients. School nurses employ many processes to systematically approach client's care needs. The school nurse might employ any of the following processes: 1) nursing, 2) research, 3) health education, 4) epidemiological, 5) administrative/management, 6) planned change, 7) legislative and 8) contract-setting. An example of systematic process

might be a school nurse reviews medical records on a new student who is transitioning from middle to high school. The student has a medical condition that is unfamiliar to the nurse and records are sparse. The nurse uses a methodical approach to review records and perform research on the medical condition to develop a plan for care in the high school, taking into consideration the changing environmental challenges of a large multi-story school building, requirements for credits needed for graduation and the federal requirements for provision of quality education in the least restrictive environment (Wold, 1981; Wold & Dagg, 2001). Daily the school nurse uses multiple processes in a systematic manner.

The tools utilized by school nurses include nursing assessment, nursing history and nursing diagnosis. The school nurse has various instruments to assist in the collection, recording or determining nursing diagnoses. A systematic nursing assessment tool might be an empirically tested tool such as a valid and reliable preschool screening tool selected by the state department of education. Other tools might include such things as an otoscope, thermometer, computer, stethoscope, template of health history forms, audiometer and others utilized frequently by school nurses (Christensen, 1981; Wold, 1981; Wold & Dagg, 2001). School nurses employ a variety of tools to facilitate the development of nursing diagnoses necessary for planning care of students.

The last concept in the framework is helping relationships. The school nurse utilizes “self” as a tool to establish and develop relationships with clients or individuals important in the life of clients for the sole purpose of promoting the achievement of the identified client goals. The school nurse’s ability to establish helping relationships depends on his/her belief system; beliefs about children, about the nursing profession,

about the educational system, and about “the nature and purposes of man and society” (Wold & Dagg, 2001, p. 402).

School nurses proficient at establishing helping relationships demonstrate expertise with interviewing and listening and have an attitude of genuineness or realness which is not a façade but an integral part of the persona presented to clients. It is of great importance for the school nurse to establish and maintain helping relationships in order to be successful in assisting clients to reach their potential and achieve their goals. School nurses are viewed as helping persons by educators, administrators, parents and students. Different than educators and administrators, the school nurse in the role of a helper can be trusted by students as there is no direct authority or control exerted by the school nurse over the students’ lives in the school. This trusting demeanor encourages students to approach the nurse for assistance with problems without fear of reprisal or judgment (Schultz, 1981; Wold & Dagg, 2001). An example of the importance of helping relationships would be the instance of a student who is seen three or four times in a week without a recognizable physical problem. The school nurse recognizes that frequent visits might reflect an unidentified problem. The school nurse interviews the student and listens for clues to the real reason for the frequent visits. The student explains their concerns about feeling isolated, no friends at school or in their neighborhood. The nurse continues to listen and offer support, asking the student to return for additional conversations which eventually lead to a plan to contact the parent, teacher, and counselor. Once the student has established goals to improve social encounters, the school nurse monitors the results of the plan and identifies and improvement in grades and attendance, along with fewer visits to the health office. The student has directly

benefited from the ability of the nurse to act as a helper and establish and maintain a helping relationship.

The five concepts of the conceptual framework for school nursing practice have been described. Realistic examples for each concept have been described. Next the utilization of this framework in school nursing literature will be probed.

Search strategies.

The SNFP was used to develop questions for the semi-structured interview guide. Therefore, it is important to determine how the framework has been represented in nursing literature. The first step taken was to search Google Scholar. Google Scholar was chosen as the first approach because there is functionality in Google Scholar that allows the researcher to enter the name of the article or book and a hyperlink "cited by" appears as an option. If this option is chosen then publications where the article of interest is in the reference list are displayed for the researcher. The article published in 2001 is a reprint of the 1978 article; there were five articles which contained either article of interest as a reference. Only one of these articles was published within the last ten years. Three were more than 15 years old and one was not written in English. The book published in 1981 which also contains the original 1978 work had 50 "cited by" possible articles. Of these, the majority were greater than 15 years old. This researcher focused on articles written since the reprint of the original 1978 article in 2001. There were ten references chosen for review. One was a thesis written prior to 2001 but appeared to have elements within the research question most similar to this research. Two other articles were chosen prior to 2001 one which was appropriate to include in the review and one which was not appropriate for review as it only made a passing reference to the

framework as representing a standard for care planning. In total, eight articles and one thesis were reviewed and will now be presented.

School nursing framework for practice in school nursing literature.

The first study to mention the school nursing framework for practice (SNFP) is a master's thesis on the attitudes of school nurses toward care planning for special education students (Fischer, 1995). Fischer interviewed 10 school nurses utilizing semi-structured interviews. The framework utilized in this research was a framework on attitude and not related to school nursing practice. The only mention of the work of Wold and Dagg was the recommendation for school nurses to develop and maintain a detailed health record and plan in collaboration with the client (Fischer, 1995). This research might have expanded on the work of Wold and Dagg as a number of the interview questions focused on concepts included in the framework. Fischer's work was before the reprint of the original article in 2001 so might have excluded the SNFP because of the age of the original reference.

Bradley (1998) described the rationale for establishment of a research agenda for school nursing. She based her argument for establishing the agenda on the acceptance of the SNFP. She describes the SNFP as a "common theory" (Bradley, 1998, p. 55) without establishing this framework as a theory through scientific inquiry. There appears to be an assumption on the part of this author that the SNFP is an agreed upon theory in this nursing specialty in spite of the lack of scientific review to support the framework.

In some instances, an individual concept from the Wold and Dagg framework has been described in school nursing literature. The need for expertise in establishing helping relationships was highlighted in a reference describing how a nursing school in North

Carolina could support school nurses and school districts in rural areas (Adams & Scheuring, 2000). The partnership between nursing schools and school districts was established to improve health outcomes in students and to address six guidelines for improvement including: 1) long range planning for coordinated school health, 2) develop and deliver basic school health services, 3) establishment of profession development of school nurses, 4) collaboration among stakeholders in the community, healthcare and educational systems, 5) standardize school health activities and 6) local level programming decisions for in-school services. An outcome of this partnership was to establish within the nursing school a course to prepare graduating nurses for school nursing practice. The school districts and school nurses benefited from the relationship as gaps in the healthcare needs of students were met when student nurses had opportunities to present educational sessions on health topics to elementary students within two targeted high risk schools (Adams & Scheuring, 2000). The entire framework for nursing practice was not addressed only the ability to establish helping relationships and contracting with clients for goal setting. Benefits from the helping relationship were identified by the school districts and the student nurses. School districts were able to provide educational sessions on health topics to a targeted audience of at risk students and student nurses gained experience with school nursing.

One author encouraged school nurses to become actively involved in the three stages of public health prevention, primary, secondary and tertiary as part of the management of asthma in school children. Public health is one of the concepts included in the SNFP. In particular the author's focus on tertiary prevention encouraging school nurses to manage and deliver health care services, advocate for children's health rights,

provide counseling for children and families and provide health education to school staff. All these efforts are focused on reducing the impact of asthma on the child's educational success by focusing on the public health component of the framework (Huss, Winkelstein, Calabrese, & Rand, 2001). Again, only one concept of the five in the framework is highlighted in this paper.

In a report on the importance of school nursing research for school nurses in practice, the author refers to Wold and Dagg (1981) as supporting the need for school nursing research. The report describes the key issues and needs on which school nursing research needs to focus (Hootman, 2002). The SNFP was not utilized as a framework to guide the process utilized to identify research needs. The framework appeared to be secondary even though it might have supported an agenda for school nursing research based on the concepts in the framework as a guide to suggest research questions of importance to school nursing.

Autonomy of practice in school nurses was the focus of one qualitative research study. Twelve subjects were interviewed. Both novice and experienced school nurses participated in the research. The author utilized the work of Wold and Dagg (1981) to highlight the five roles of school nurses: manager, health service deliverer, child advocate, counselor and health educator. These roles reflect some of the autonomous activities inherent in school nursing. The author labels the SNFP as "definitive", strong words for an as of yet untested framework. The results of the study indicate there was a difference between novice and expert nurse in the area of role perception, comfort and confidence. The findings of this research suggest that novice nurses might benefit from mentoring from experienced nurses in order to assist the novice school nurse in

developing a sense of fulfillment in their autonomous role (Simmons, 2002). Again, the framework was not utilized to inform the research, only to describe potential autonomous roles for a school nurse.

Another framework related to school nursing has been proposed to address the community of school nurses. Different than the SNFP, this framework describes concepts related to school nurses as a community of individuals not related to the community they serve. The four concepts of this framework are physical factors, social and cultural factors, community organization and individual behavior (Christeson, 2003). It is evident that this framework does not overlap with the SNFP as the concepts are quite divergent. The author of the school nurse community framework acknowledges the SNFP influences the National Association of School Nurses *School Nursing: Scope & Standards of Practice* (National Association of School Nurses, 2005). Within these scope and standards, the SNFP guides the philosophy, expectations, and defines roles and goals for school nursing practice. Clearly the SNFP is playing an influential role in school nursing practice especially when accepted by the national professional organization representing school nurses.

A framework for understanding clinical reasoning in community nursing was developed by Carr (2004). In this framework the nurse serves individuals in the community. The community nurse focuses on the context of the patient in their home and community and how that impacts solutions developed to address health needs. The author acknowledges there are certain concepts common to all nursing such as health, need, care and partnership. The framework was modeled after the SNFP concept design with four steps: naming, framing, need identification and action options. Each of these

concepts is defined and mimicking the SNFP a visual representation has been produced. This framework, similar to SNFP, is designed with a cluster of concepts reflecting that which is unique to community nursing (Carr, 2004). Here is another example of a nursing framework specifically designed to describe the work of a specialty nursing group designed by an author who recognized the contribution and adapted the work of Wold and Dagg.

Loneliness among students is the subject of another publication. In this publication the school nurse's role in assisting students experiencing loneliness is described. Skills utilized by school nurses such as interviewing and listening come directly from the SNFP concept definitions. These skills aid the nurse in communicating with the student. Employing these techniques allows the school nurse to develop a helping relationship with the student. As a result of this relationship, the student is encouraged to develop meaningful connections to other school personnel thus reducing the sense of loneliness (Krause-Parello, 2008). Again only one concept is identified as assisting the school nurse to serve the student, that of helping relationships. Certainly the other concepts play a role but are not highlighted in this article.

Unlike many theories or frameworks, there did not appear to be a test of the framework through peer reviewed research. This researcher wanted to confirm that in spite of due diligence, she had failed to discover the seminal references that might have tested the framework. Seeking to be thorough, this researcher contacted the developers of the framework directly asking the question "Do you know of any research that utilized your framework?" and "Have you done any further work on the framework or do you know of anyone who has expanded, tested or developed it further?". To these questions I

received negative answers from both authors, Susan Wold and Nancy Dagg. Following the publication of the book in 1981 they moved on to different areas of interest in nursing and to their knowledge no further work had been performed to validate or test the framework or the concepts within the framework (Dagg, 2011; Wold, 2011). Feeling as though the search had come to an end this researcher was excited at the prospect of taking a fresh look at this now 30+ year old untested framework and to place it at the center of the design of this research. This move allows this researcher to create new knowledge about the framework and explore the continued relevance of the concepts and model after more than a quarter century.

Chapter Summary

This chapter has reviewed the literature relevant to care coordination for CSHCN in the healthcare and educational systems. Evidence for positive outcomes of school nursing interventions on behalf of CSHCN was presented. A review of the literature where the SNFP has been referenced was presented. The literature support care coordination as a beneficial tool in promoting access to appropriate healthcare, reducing healthcare costs, improved quality of life scores or perceptions and potential impacts on educational performance. Support for the school nurse assuming the role of care coordinator was developed. Finally, this research represents for the first time where the SNFP was central to the design of a school nursing research study.

CHAPTER 3 METHODS

In this chapter the aims, design and methodology for data collection and analysis are described. The rationale for the study design and analysis is presented. An analysis plan is outlined for each study aim. Finally, the concept of trustworthiness and how it is maintained throughout this research is discussed.

Study Aims

The overall purpose of the study was to identify the factors which impact school nursing care coordination for children with special healthcare needs. The specific study aims addressing this purpose were to:

1. Explore school nurses understanding of care coordination and how they perceive their role in relationship to care coordination
2. Describe tools/ resources used for planning care coordination activities
3. Describe the systematic process used for planning and communicating care coordination activities
4. Describe the impact of helping relationships on planning and communicating care coordination activities
5. Identify factors associated with facilitating care coordination activities
6. Identify factors which inhibit care coordination activities

Participants

Participants in this study were licensed school nurses (LSNs) registered by the Minnesota Department of Education and currently employed by a school district in the State of Minnesota. There are approximately 1100 school nurses licensed by the State of Minnesota, Department of Education (Ward, 2010). The qualifications for a Minnesota school nurse are: licensed by the Minnesota State Board of Nursing as a registered nurse with a minimal background of a bachelor's degree, along with a Minnesota State Board of Nursing certification as a public health nurse and completion of an intense background check for initial licensing. Yearly, licensed school nurses undergo a less intense background check as a condition for continued employment by a school district (Minnesota Administrative Rule 8710.6100).

There is no comprehensive list of LSNs who are currently employed so it was not possible to contact LSNs directly. Therefore a two pronged approach was taken to reach as many Minnesota school nurses as possible to invite their participation in this study. Recruitment of LSNs for the study began by obtaining a list of all Minnesota school districts and all Minnesota public health departments outside the large metropolitan areas of Minneapolis, St. Paul, Rochester and Duluth. These are the four largest cities in the state and are known to have LSNs as district employees. The lists of school districts and public health departments are publically available on the State of Minnesota Department of Education and Department of Health websites (Minnesota Department of Education, 2011a; Minnesota Department of Health, 2011a). Some districts contract school nursing services through local public health departments. These contracts are between the school district and the public health department; no comprehensive lists of these relationships

exist. Therefore, all public health departments were included in the recruitment strategy except for those within the large metropolitan areas.

An introductory letter was mailed to all lead school and public health nurses. All letters were addressed with a generic title of lead school nurse or lead public health nurse. The letter explained the study and asked for the lead nurse to share the invitation with their staff of LSNs or public health nurses. The letter requested the LSNs interested in participating in individual semi-structured interviews to contact the researcher by e-mail or telephone. A total of 402 letters were mailed to school districts and public health departments. A copy of the recruitment letter can be found as Appendix A.

The second recruitment tactic was to contact the president of the Executive Board for the School Nurses Organization of Minnesota (SNOM). SNOM is an organization affiliated with the National Association of School Nurses (NASN) and represents approximately 450 LSNs (40-50% of Minnesota LSNs) (Herrmann, 2010). This group of nurses represents some of the leaders in the field of school nursing and represents LSNs across the State of Minnesota. A request was made to distribute the invitation to participate to SNOM members. The president of the Executive Board agreed to distribute the invitation using the group e-mail function of the SNOM list-serve. The e-mail contained a statement from the SNOM president supporting the research and encouraging Minnesota school nurses to participate. Potentially, school nurses could have received an invitation through the SNOM list-serve and the recruitment letter sent to school district lead school nurses and public health districts. A copy of the SNOM e-mail can be found in Appendix B.

Within a week of the mailings and e-mail release, participants began to contact the researcher. The majority of contact was through the researcher's e-mail address. The researcher contacted each potential participant by phone to review the inclusion criteria questions (Appendix C). If the LSN qualified for the study by answering the questions, an interview was scheduled. The LSN had the option to select a time and place or a phone call for the interview. The recruitment and interview period lasted for one month.

Recruitment summary.

A total of 36 LSNs contacted the researcher for possible participation. This represents approximately 3% of the estimated number of school nurses in the state of Minnesota. Three of the potential participants did not meet the criteria for inclusion; they were not providing direct care coordination activities to CSHCN. Four participants indicated interest and repeated phone calls were made to the LSNs with messages left for them; upon no response they were excluded from the study. Although two LSNs contacted the researcher at the end of the recruitment period, they were advised that a sufficient number of subjects had been recruited but their names would be retained in case additional interviews were needed. The additional participants were not needed and therefore these persons were notified that the study was complete. The remaining twenty seven subjects completed the interview and demographic survey. See Table 1 for a summary of participant recruitment.

Table 1

Recruitment summary

Category	**Number**	**Total**
Total subjects interested	36	36
Subjects - excluded	3	33
Subjects - failed to reach	4	29
Subjects - responded after enrollment phase	2	27
Final number of participants		**27**

Setting

The study included LSNs from public school districts within the State of Minnesota. Minnesota has 336 identified public school districts containing over 2000 individual schools and more than 825,000 students (Minnesota Department of Education, 2011b). According to state law, school districts of 1000 or more student must either employ licensed school nurses or contract school nursing service from a private or public health agency to provide for the healthcare needs of their students (Office of the Revisor of Statutes, State of Minnesota, 2010). Individual school districts determine which avenue for school nursing service they will pursue based on their budgets and policies.

Key Definitions and Terminology

Key definitions and terms are provided for the reader. The definitions represent the key concepts contained in the research question. The four terms defined are terms common to the special education system which might be unfamiliar to the reader.

School nurse.

School nursing is recognized by National Association of School Nurses (NASN) as "A specialized practice of professional nursing that advances the well-being, academic success and life-long achievement and health of students. To that end, school nurses facilitate positive student responses to normal development; promote health and safety, including a healthy environment; intervene with actual and potential health problems; provide case management services; and actively collaborate with others to build student and family capacity for adaptation, self-management, self advocacy, and learning" (National Association of School Nurses, 2010, para. 1).

The roles and professional stature of the school nurse have been identified. A simplified definition of a school nurse is a specialized professional nurse that advances the well-being, academic success and lifelong achievement of students (Gordon & Barry, 2006). For this research a school nurse required state licensure as a school nurse, was employed, and had a regular assignment in a public school district in the State of Minnesota.

Children with special healthcare needs (CSHCN).

Children with special healthcare needs are " those who have or are at an increased risk for a chronic physical, developmental, behavioral, or emotional condition and who

also require health and related services of a type or amount beyond that required by children generally" (Newacheck et al., 1998, p. 117). For this research a CSHCN is any child enrolled in an elementary, middle or secondary school in the State of Minnesota who has a chronic medical condition that requires very frequent or daily school nurse contact, has health problems that require care coordination or management at school or children whose chronic medical condition makes them at higher risk for absenteeism.

Care coordination.

At this time there is no agreed upon standard definition of care coordination (Wise, Huffman, & Brat, 2007). This researcher reviewed current literature to develop a definition which was appropriate for the study. Care coordination was defined as a process for patients and families to be linked across systems so their needs and preferences are facilitated to achieve optimal health.

Care coordination in this study combines the concepts from six references as applied to CSHCN in this study: 1) linking patients and families across a variety of healthcare settings, 2) needs and preferences are facilitated, and 3) achieving optimal health for a vulnerable population (Kruger, 2004, Lindeke et al., 2002, Looman & Lindeke, 2008, Presler, 1998, Watson, 2010, Council on Children with Disabilities, 2005; Ziring et al., 1999). For the purposes of this study the definition for care coordination for CSHCN now becomes a process by which patient and families are linked across health settings to have their needs and preferences facilitated to achieve optimal health. Similar to the mantra for informatics, the right information on the right patient at the right time, the goal of care coordination can be expressed as the right care for the right patient at the right time (Watson, 2010).

Terminology.

Four specific abbreviations and terms are contained in this dissertation:

- **Individualized Education Plan (IEP):** A legal document prepared by school personnel for a student who qualifies for special education services. The plan contains the present level of performance, the goals and objectives along with accommodations necessary to meet the goals and objectives.

- **Individualized Healthcare Plan (IHP):** A plan of action prepared by a school nurse to manage potential or actual healthcare needs. Outcomes of the plan are monitored by the school nurse. The school nurse might delegate to unlicensed personnel certain actions in the plan.

- **Emergency Care Plan (ECP):** A written plan for students with chronic conditions. The plan includes step by step instructions describing the actions to take in an emergency. Common conditions where a school nurse might write an ECP include severe allergies, asthma, diabetes and seizure disorders. ECPs are not necessarily related to the IEP.

- **504 Plan:** This type of plan is developed for students who have a physical or mental limitation that does not impact their ability to learn or limit their educational performance

Research Design

The design of this research was a qualitative descriptive study. Qualitative descriptive design has been described as capturing knowledge that is basic, fundamental

and surface. This does not mean it is any less valid or rigorous than other qualitative research designs. The basic, fundamental and surface design suggest that qualitative description seeks not to interpret or analyze the event in terms of some preselected conceptual or abstract framework; instead it seeks to present the facts in language which is understandable to the target audience. Sandelowski (2000) states "qualitative descriptive studies offer a comprehensive summary of an event in the everyday terms of those events" (Sandelowski, 2000, p. 336).

Qualitative description design was appropriate to answer the research question posed: What factors impact school nurses ability to perform care coordination activities for children with special healthcare needs? This design fits the state of the science and the type of research question being asked, "What are the concerns of people about an event?" (Ayres, 2007, p. 133). This research is composed of three components including: 1) the concern is factors impacting, 2) the people are school nurses, and 3) the event is the care coordination for CSHCN.

One of the most well respected qualitative researchers, Margarete Sandelowski, supports the use of qualitative description as a viable and reasonable research approach by noting that qualitative description is a "distinctive method of equal standing with other qualitative methods" (Sandelowski, 2000, p. 335). The strengths of qualitative description as a method result from the fact that it is 1) well established, 2) a design where the researcher does not stray far from or deeply into the data, and 3) the data are not highly conceptual nor are the data highly abstracted. In this research study these strengths help support the findings of the research. The data analysis results in development of themes which represent in clear language the factors which impact school

nurses care coordination for children with special healthcare needs. Qualitative description analysis produces a complete and valued end product that serves as a prelude for further inquiry.

When conducting a qualitative descriptive study the researcher stays close to the data. Staying close to the data implies the researcher does not analyze the data searching for relationships nor does the researcher interpret the data in light of a predetermined conceptual or abstract framework. Instead the qualitative descriptive researcher examines the data looking for themes and commonalities among the data without altering, interpreting or interfering with the data. The descriptive researcher takes time and effort to present the facts in a manner that is clear and understandable, in everyday language. The purpose of the language of the qualitative descriptive researcher is to communicate rather than to interpret the findings (Sandelowski, 2000).

Design features of qualitative description.

Qualitative descriptive studies have certain specific features related to sampling, data collection, data analysis and techniques of representation of the data. Qualitative descriptive studies have no pre-existing conformance to a particular theory or philosophy. Instead the researcher takes a naturalist approach in the study which seeks to study phenomenon in the natural context or setting. This approach has overtones of an ethnographic study. Ethnography studies individuals in the natural state and might use observation, interviews or questionnaires for data collection. Qualitative descriptive studies utilize similar data collection methods but focus on the analysis of phenomenon rather than analyzing individual's behavior or societies of individuals or cultures. The researcher demonstrates this commitment to the naturalistic approach by purposely not

pre-selecting variables to study, manipulating the variables or applying a theoretical framework for interpretation of the data. Therefore, this research design might result in the most unclouded representation of the data collected (Sandelowski, 2000).

The technique for sampling in qualitative descriptive studies is purposive, seeking to maximize the variation in the sampling. By maximizing the variation of the sample the researcher hopes to gather the full breadth of the phenomenon under investigation. This sampling approach seeks to highlight the unique features of the study phenomenon over a broad range of the individuals impacted by the phenomenon. The data collection is directed toward collecting the "who", "what" and "where" of the target phenomenon. The most appropriate data collection technique utilizes moderately structured or open ended questioning with focus groups or individuals.

The data analysis choice for qualitative descriptive studies is content analysis (Krippendorff, 2004). This analysis technique systematically applies codes to the textual data. The codes are derived from the data itself during the course of the study. The data is simultaneously collected and analyzed which allows for an interaction between the processes. Some pre-conceived coding structures might exist but are always amenable to change based on the data collected.

Finally the data representation is a straight forward descriptive summary resulting from the data analysis. The information contained in the summary reflects the best fit of the data collected. The representation of the data in summary form serves both as the end product of the research and as an entry point for future research. The summary might result in hypotheses, concepts or thematic moments which are appropriate for study and testing (Sandelowski, 2000). What is evident is qualitative descriptive research is a long

standing qualitative research design utilized to study phenomenon that are poorly understood and have little theoretical background and where the researcher seeks to describe the phenomenon, laying the groundwork for future studies. These characteristics are met in this study.

Data Collection Methods

Two types of data were collected during this study. Qualitative semi-structured interviews provided the data to address the research question. A demographic survey was administered to all participants for the purpose establishing context through collection of demographic data on the school nurses and the districts for which the school nurses were employed. This research was approved as an exempt study by the Institutional Review Board at the University of Minnesota. The exemption was based on the fact that all participants were adults, they were not being questioned on a sensitive topic and they would need to contact the researcher if they wished to participate. All participants were informed that they could discontinue the interview process at any time without malice. To protect their identity, participants were assigned a number which identified the transcript and field notes related to the interview tape. The participant names were associated to the assigned number in the researcher's journal and were accessible only by the researcher.

Development of interview guide and demographic survey.

Part of preparing for semi-structured interviews was the development of an interview guide. An interview guide, found in Appendix D was structured around the SNFP and the study aims. Three questions in the interview guide specifically addressed concepts from the SNFP, systematic process, tools and helping relationships. The remaining questions addressed the study aims of understanding care coordination, the

role of the school nurse in care coordination and factors which inhibit or facilitate care coordination.

The demographic survey, found in Appendix E was designed to collect information on the school nurse, the school and the school district where the school nurse is employed. General demographic questions were collected such as age, gender, number of school buildings responsible for, educational background and nursing experience. The school specific information collected was the type of school, enrollment, free and reduced lunch rate, and special education rates. The school district information collected was size of the district. The school nurses were not asked to identify the location or name of the school district. This information was purposely left out to protect the identity of the school nurses. Potentially a school nurse could be the only school nurse in the district and therefore identifiable.

Qualitative semi-structured individual interviews.

Prior to the beginning of the interview and collection of demographic data, the participants provided verbal consent to participate. A standard statement was read to the participant and the interview did not begin until the LSN stated agreement to participate. A copy of the statement can be found in Appendix F. Each participant was advised that the interview was to be recorded. An Olympus WS700M digital recorder was used for each interview. Once the interview was complete, the digital file was uploaded to a secure website on the University of Minnesota server using Netfiles. The professional transcriptionist was provided a URL and password to retrieve the file for transcribing the interviews. Copies of the transcribed interviews were uploaded to the secure server as well.

The primary method employed in data collection for this research was individual semi-structured interviews with LSNs to capture school nurses' perceptions of factors impacting care coordination activities. There were two components to the interview: the LSNs narrative about an instance of care coordination for a CSHCN followed by semi-structured questions. The interviews began with the researcher asking the participant to provide a narrative of an instance where the participant provided care coordination activities for a CSHCN. The participants were allowed to select a student to use in an example. They were not coached in advance about the type of narrative that would be needed for research. The instructions given at the time of the interview were to tell the researcher about a memorable instance where they had to provide care coordination for a CSHCN. They were advised to refrain from using the name of the student or any reference to themselves or their school or school district. If by mistake the LSN mentioned a name of themselves, their district or other school personnel the transcript was modified to remove the name and replace it with an underscore to indicate a missing word.

Once the narrative portion of the interview was complete, the semi-structured interview guide was used to focus questions on the study aims. If some of the semi-structured questions were already answered during the narrative portion of the interview, participants were not asked to repeat their responses again for specific interview questions. When answers to questions were unclear or uncertain as to meaning, additional probing questions were asked. Interviews lasted between 30 and 45 minutes but each subject was asked to plan for 60 minutes to complete the interview.

Demographic survey.

A written survey accompanied the interview to capture school nurse characteristics along with information regarding the schools and districts to which the school nurse is assigned. This survey provided contextual information regarding the environment of the school nurse's practice. The questions included information on the school nurse, the schools they are responsible for and the school district which employs them. Participants who agreed to be interviewed were sent a copy of the demographic survey by e-mail prior to the scheduled interview time. These data were collected at the beginning of the phone call or face to face meeting prior to conducting the interview. If there was any information unavailable at the time of the interview, the LSN was advised to send the information to the researcher by e-mail. If after one week the information was not submitted, a follow up e-mail was sent to the LSN reminding the LSN to send the information.

Field notes.

During the interview some observational notes were taken to augment the transcribed interviews. Once the interviews were transcribed this researcher listened to the interviews again. While listening, the interview audio file was compared to the transcript. Any errors or omissions to the transcripts were corrected. Additional notes were taken on each interview with key words noted for each interview question in the guide. These key words were used to develop some of the codes during the analysis phase.

A personal journal was kept documenting the impressions and highlights of the interviews along with decision points regarding saturation, findings and confirmation from other interviews. This journal serves as an audit trail to support the trustworthiness of the study and the data analysis process. This journal also served to guide the researcher in the discussion section of the dissertation. Observations made during the analysis phase and during the preparation of the results were noted to include in the discussion section.

Data Analysis

This research contained both qualitative and quantitative date. Plans for analysis of both types of data are presented. The qualitative data plan seeks to address the study aims. The quantitative data analysis develops a contextual picture of the participants and the environment where they provide care coordination for CSHCN.

Qualitative data analysis plan.

Content analysis was the analysis technique applied to this research (Krippendorff, 2004). Content analysis is a systematic process by which the researcher reads texts, images or symbolic matter from the perspective of the participant, not the researchers' perspective. Qualitative researchers use content analysis as a research tool or technique to provide new insights, increase understanding of a particular phenomenon or to inform practical action. Simply stated, "content analysis is a research technique for making replicable and valid inference from texts (or other meaningful matter) to the contexts of their use" (Krippendorff, 2004, p. 18).

One challenge with qualitative research is the enormous amount of data obtained from participants. It is difficult as a researcher to determine from the vast amount of data

what matters the most as all the data look promising. Having a conceptual framework or solid research question is the "best defense against overload" (Miles & Huberman, 1994, p. 55). In this research, the SNFP provided guidance for selection of the questions utilized in the interview process and this same framework supports the analysis of the data. This researcher's own opinions or biases were put aside to allow the text to guide the analysis.

Coding scheme.

The development of the coding scheme directly impacts the results obtained. Therefore it is important to describe the coding scheme and how it was developed. NVivo9 (QSR International Pty Ltd, 2010) was used to develop the coding scheme. In this application the text is read by the researcher and key words that summarize the text are used to create concepts called nodes and sub nodes. A node is a parent concept and a sub node is a child sub concept under the node. The sub node is more specific than the node. For example a parent node might be medical concern, the child node would be diabetes, spina bifida or any of a number of more specific medical conditions. Not all nodes will have sub nodes but many do.

The mechanics of the analysis involve coding the interview transcripts. Coding involves selecting portions of the transcript that represent different concepts integral to the research question posed. A coding scheme results when the researcher deconstructs the transcript into written examples of the coded concepts. The coding scheme was developed iteratively as each transcript was reviewed. The first transcript was coded with nodes and sub nodes identified. The second transcript utilized those nodes and sub nodes from the first transcript but where additional information was found that did not fit into a

previously established node or sub node then another node or sub node was created. This iterative process continued on through all 27 transcripts resulting in the final coding scheme.

Qualitative analysis plan by study aim.

Study Aim #1: Explore school nurse understanding of care coordination and how they perceive their role in relationship to care coordination

Analysis: Within the interview question guide there were three questions which prompted the participants to address this study aim. These questions were 1, 2 and 7.

Study Aim #2: Describe tools/ resources used for planning care coordination activities

Analysis: Within the interview question guide there were three questions which prompted the participants to address this study aim. These questions were 3, 4 and 5.

Study Aim #3: Describe the systematic process used for planning and communicating care coordination activities

Analysis: Within the interview question guide there was one question which prompted the participants to address this study aim. This question was 6.

Study Aim #4: Describe the impact of helping relationships on planning and communicating care coordination activities

Analysis: Within the interview question guide there was one question which prompted the participants to address this study aim. This question was 8.

Study Aim #5: Identify factors associated with facilitating care coordination activities

Analysis: Within the interview question guide there was one question which prompted the participants to address this study aim. This question was 9.

Study Aim #6: Identify factors which inhibit care coordination activities

Analysis: Within the interview question guide there was one question which prompted the participants to address this study aim. This question was 10.

Development of the coding scheme and development of themes are foundational to the process of content analysis. Coding was conducted by the researcher for this study. To develop trustworthiness of this research certain efforts have been made to assure the reader that the results truthfully represent the responses of the participants. Following the description of the quantitative data analysis plan, a discussion of the concepts of trustworthiness is presented along with the methods used in this research to ensure trustworthiness.

Quantitative data analysis plan.

Descriptive statistics were applied to analyze the survey elements. The school nurse elements described were age, gender, educational background, years of nursing experience, years of experience as a school nurse, years as a school nurse in this school district, numbers of school buildings assigned to, numbers of students in their assigned school(s), and whether it is an elementary, middle or high school. The school and district factors described were the size of the school district, numbers of students qualifying for special education services and the percent of the student population qualifying for the free or reduced lunch program. Descriptive statistics included medians, ranges and correlations of the data. The purpose of these quantitative data was to describe the context of the participants.

Trustworthiness

In quantitative research trustworthiness of the study results is described as validity, reliability and generalizability. In qualitative research, trustworthiness of the study results is described as credibility, dependability and transferability. These concepts are similar but due to the nature of qualitative data there are distinct differences which require clear definition (Graneheim & Lundman, 2004).

Credibility refers to how well the analysis and processing of the data address the research question posed. Credibility is addressed during the analysis phase in the selection of the coding scheme, the representational samples of text attributed to a concept, and finally how well themes reflect the data and answer the research question. One means of ensuring credibility is to have another researcher on the team or another person familiar with the research subject review the coding scheme. This concept is confirmability. Confirmability is different from verifiability. Verifiability implies an exact match of the coding between individuals. Confirmability reflects and agreement of experts to the manner in which the coding scheme was developed and the data sorted according to those codes (Graneheim & Lundman, 2004). The researcher met with her adviser, an experienced qualitative researcher, to present the process for coding transcripts. The adviser confirmed the logic of the coding scheme and provided feedback to improve the process. The adviser suggested the researcher define the concepts represented by nodes and sub nodes. The researcher created written definitions of the concepts for each node and sub node within the analysis software. Once all transcripts were coded, a process of peer or member checking was performed.

Dependability reflects consistency in the data over time. It is expected that over time data collection will vary and the researcher must make every effort to minimize the variability or at least account for the variation. This is most common when data collection extends over a prolonged period of time (Graneheim & Lundman, 2004). In this research there is some variability. The interview guide is a semi-structured interview tool which captures both consistent questions, but using words of participants, allows for clarification and expansion of ideas that added depth to the discovery of the factors impacting school nurses' care coordination for CSHCN. All questions on the semi-structured interview guide were addressed with each participant but might have been answered in the narrative or in a previous question. When questions were added or modified, an entry in the researcher's journal was made to offer an audit trail of the decision points in the study. The data collection period of less than one month supported data collection consistency by the proximity in time for all the interviews. Additionally in review of transcripts a member check was performed by another qualitative researcher to evaluate whether the investigator used leading questions or remained neutral during interviews.

Another criterion of trustworthiness is transferability. This is defined as the ability of the reader to see the applicability of the findings to other settings. The reader makes a judgment as to the value the findings have within their culture or context. Within the findings, the presentation of appropriate examples quoted directly from the transcripts adds to the richness of the finding and adds to understanding of the reader (Graneheim & Lundman, 2004). The findings of this research were rich with quotations which exemplify the themes. The context of the study was clearly described through the

collection and analysis of demographic survey data and coding of particular concepts in the qualitative data. The reader is able to judge from the results reporting whether the results can be transferred in part or in the whole to their circumstance; whether it is applicable to them.

Addressing all three concepts, credibility, dependability and transferability, ensures the trustworthiness of the study. Trustworthiness relies on the researcher's ability to present the clearest, most concise argument for the most probably interpretation of the data. Trustworthiness measures the integrity of the researcher, the rigor applied to the research and the interpretation of the findings.

Ethical Considerations

This study received the designation as an exempt study from the University of Minnesota's Institutional Review Board (IRB). The IRB determined there was minimal risk to the research participants; they were all adults and all had to initiate contact with the researcher if they wished to participate. The IRB did not require a consent form to be completed but assumed consent by the willingness to participate in the interview. At the time of the interview a statement was read to the participant. The participant verbally agreed to the interview and acknowledged they understood they might discontinue the interview at any point without consequences. The statement was not retained as a portion of the transcribed interview.

Chapter Summary

The researcher used a qualitative descriptive design to study the factors which impact school nurses' ability to perform care coordination activities for children with

special healthcare needs. School nurses during semi-structured interviews described their experiences with care coordination beginning with a narrative of a memorable case where they provided care coordination. The interview questions were devised to reflect concepts in the SNFP. The interviews were analyzed utilizing content analysis supported by a coding scheme devised of nodes and sub-nodes. From this coding scheme themes related to the concepts in the SNFP and facilitators and barriers to care coordination were identified.

CHAPTER 4 RESULTS

In this chapter the results of the survey and semi-structured interviews are presented to describe the study participants and school districts they serve and address the specific study aims. In this chapter first the results of the survey are presented, followed by a summary of how the coding scheme was developed and trustworthiness of the scheme establish. Next results from coded interviews describe contextual data about the medical concerns of students and family issues, and then specific aims of the study are addressed.

The primary aims of this study were to:

1. Investigate school nurses understanding of care coordination and how they perceive their role in relationship to care coordination
2. Describe tools/ resources used for planning care coordination activities
3. Describe the systematic process used for planning and communicating care coordination activities
4. Describe the impact of helping relationships on planning and communicating care coordination activities
5. Identify factors associated with facilitating care coordination activities
6. Identify factors which inhibit care coordination activities

Description of Participants

Participants in all research bring to the study their point of view, experience, and background. In order to understand the themes developed and the quotations selected to represent the themes, it is important to understand the context of the participants. The

contextual data comes from two sources. One source is the demographic survey and the other is from the qualitative interview data mainly gathered in the narrative portion of the interview and through additional probing questions.

A summary of the quantitative data collected from the Collection of Survey Data form is presented in Table 2.

Table 2

Summary of Collection of Survey Data results

Nurse and School District Characteristics	**Median**	**Minimum**	**Maximum**
Age in years of school nurse	56.5	26	64
Years of nursing experience	34	2	39
Years as a school nurse	7.5	1	33
Years at this district	7.5	1	33
Number of schools responsible for	7	1	17
Number of students responsible for (student to nurse ratio)	2450	300	3500
Number of students in school district	6875	300	34570
Percent students in special education	12.6%	5%	100%
Percent students on free or reduced lunch	39.6%	10.5%	83.1%

All participants were female with at least a bachelor's degree. Nearly half (48%) of the participants had a graduate degree. Many of the participants reported graduate degrees outside of nursing; 44.4% with a master's degree and 3.7% with a doctoral degree. Master's degrees were reported in the fields of education, public health, human

development and public health administration. Twenty of the twenty seven participants (74.8%) were over the age of 50; sixteen (55.3%) had over 25 years of experience as nurses. The majority of the participants remained employed by that same school district once starting a career as a school nurse within that particular school district.

Only four of the participants had responsibility to cover a single school building. The vast majority covered multiple buildings spanning all ages and grades. The school district size ranged from very small at 300 students to one of the largest in the State of Minnesota. The nurse to student ratio ranged from 1:300 to 1:3500 with only four participants monitoring the health of 750 or fewer students. Twenty-five of the participants reported between 10% and 20% of their students qualified for special education. The range of students qualifying for free or reduced lunch (a measure of poverty) was very broad with one school only having 10% of students qualify while another school had 83.1% qualify.

In general these female school nurses had many years of experience as nurses and as school nurses in particular. They were very familiar with the population of students in their districts since most of the LSNs covered more than one school building and had a long tenure in their district. They had exposure to students on a regular basis with special education needs and to those who lived at the poverty level.

Description of CSHCN medical needs and family characteristics

To begin the interview the school nurse was asked to describe a student for whom the participant had provided care coordination activities. The type of student medical conditions described varied from nurse to nurse. School nurses identified two levels of concerns – primary and secondary. Primary medical concerns are defined as the medical

diagnosis stated by the nurse that established the student as a CSHCN. Primary medical concerns encountered by the school nurses included: diabetes, seizures, cystic fibrosis, Duchene's muscular dystrophy, Down syndrome, spina bifida, hives of unknown origin, myotonic dystrophy, hip dysplasia, near drowning, born without a corpus callosum, and encopresis. Secondary medical concerns are defined as physical limitations or concerns that resulted from the primary medical diagnosis. These secondary medical concerns might be addressed or included in Individualized Healthcare Plans (IHPs). The school nurses described secondary medical concerns such as: history of chemotherapy resulting in diabetes, weight control issues, behavior problems, non-compliance with medical care regimen, autism, lack of medical supplies, toileting issues, communication problems, tube feedings, ambulation problems, scoliosis, skin care issues, developmental or cognitive delays, contractures, shortness of breath, need for durable medical equipment, lack of muscle control, asthma, thyroid dysfunction, tracheotomy tube in place, frequent fractures, kidney transplant, learning disabilities, bowel obstruction, frequent surgeries, and attention deficit hyperactivity disorder (ADHD). The school nurses interviewed manage and coordinate care for students with a wide variety of primary and secondary medical concerns.

Understanding some of the students' family characteristics the school nurses were faced with also helps to develop the context in which the school nurse performs care coordination activities. The family characteristics identified included: poor families, difficult social settings, language barriers, eviction from apartments, lack of adequate housing for a CSHCN, parents unavailable during the day, parents with chronic health conditions, financial concerns, family is overwhelmed, split home setting (parents living

apart), anger issues, recent immigrants, family or personal stress, very young parents, low health literacy, parental lack of follow through on school nurse requests for information, medications, etc., family distrustful or intimidated by health or educational system, lacking mental capacity, family supportive and involved, desiring control, in survival mode, limited education, lacking insurance, illegal aliens, cultural differences, level of investment in the child's success, divorces, and legal trouble. Most of these characteristics described suggest some limitation to the family that makes it more difficult for the family to gain access to the needed services for their child.

In summary this group of school nurses was highly educated and experienced in school nursing. They provide services to a large number of children with a wide variety of medical concerns. The students and families carry additional medical and social concerns that must be considered when providing care coordination activities.

Coding Scheme

The results of the coding scheme are now presented. Development of the coding scheme begins by identifying nodes and sub nodes within the raw transcript data. Nodes represent larger concepts and sub nodes are more discrete concepts related to the primary node. This first step of applying the coding scheme to the transcripts provides a hierarchical structure to the data and begins the deconstruction process. Eventually the raw textual data was deconstructed into 12 primary nodes with 48 sub nodes. When all nodes and sub nodes were identified an additional step was taken to map the nodes and sub nodes related to the study aims and interview questions. This mapping can be found in Table 3. Table 3 provided an organized structure which now was used by the

researcher as a map to find and develop themes across participants, across nodes and sub nodes.

Table 3

Summary of node/sub nodes and the related study aims and interview questions

NODE	**SUB NODE**	**STUDY AIM**	**INTERVIEW QUESTION NUMBER**
Medical Concern Identified	Primary medical concern Secondary medical concern	Contextual	
Family Characteristics		Contextual	
Role and Responsibility in Care Coordination	Support for families Support for students Support for teachers Indentify the problem Support for district or school Liaison for medical providers Knowledge of available services	#1	#2
Type of Plans Developed	People involved in planning Reason for plans Shared plan with Nursing terminology in plans Plans from professional	#1	#7

	organizations Review of plans with family/ health care provider People managing plans Plan sign off Individualized plans		
Identification Means	Questionnaire People involved in notification Nursing review and assessment of need Welcome Center Public health Team meetings within school Parents	#1	#1
Administration		#1	
Information Sources	Standard forms Books Internet Other school nurses Other school staff Medical Records	#2 and #3	#3

	Other health professionals Professional organizations/SNOM Journals In-services/ conferences Parents School health file		
Completeness or Accuracy of Information		#2	#3
Resources Available	Standardized plans	#2	#4, 5
Communication Process	Hard copy of plan Computerized communication System used One to one demonstration or communication IEP meetings Notebook or list	#2 and #3	#6
Helping Relationships	Trust	#4	#8
Care Coordination	Facilitators of care coordination Inhibitors of care coordination Examples of care coordination Activities	#5 #6 #1	#9 #10

Establishing Trustworthiness of Coding Scheme

Two methods of establishing trustworthiness of the coding scheme were used in this study. Prior to completion of all node and sub node coding, the researcher's advisers reviewed and approved the approach to the development of the coding scheme. Peer checking was the other method utilized to support the trustworthiness of the results. Peer checking allows another person with content expertise the opportunity to review and confirm the logic of the coding applied to a transcript. A copy of the study aims, coding scheme and one transcript was provided to an experienced school nurse who is a professor at a local university. The peer checker was asked to compare the coding scheme to the highlighted text to confirm all highlighted text could be logically represented by either a node or sub node in the coding scheme.

The peer checker validated and extended the coding scheme. The peer checker was able to associate at least one node or sub node to all highlighted passages of the text. Additionally the peer checker suggested a theme within the text which could be better represented as a separate node or sub node. The theme identified was that of collaboration between family, student, school administrators and outside agencies. The researcher noted this theme to consider for inclusion in the results but did not recode the transcripts to reflect this identified theme.

The peer checker also found five additional passages of text that could be associated with either a node or sub node of the completed coding scheme. It was noted that the coding scheme was an iterative process. Small sections of the first transcript might not have been coded as the code was not identified until a similar concept appeared repeatedly in additional transcripts. Based on the recommendations of the peer checker,

all transcripts were reviewed to ensure all text passages were appropriately coded. On review of the coding, five text passages in the first interview transcript were recoded. The first participant transcript had the most text in need of additional coding and gradually the number of text passages for additional coding diminished so that by transcript 20 there were no further passages found in need of codification. All additional passages were coded prior to the beginning of the qualitative data analysis.

Qualitative Data Analysis

During the qualitative data analysis a three step process was applied to deconstruct and then reconstruct the data into node or sub nodes, themes and factors. Twenty seven transcripts were available for analysis. These 27 transcripts contained over 360 pages of raw text. Passages of raw data were highlighted as representing nodes or sub nodes of the coding scheme. Nodes and sub nodes identify concepts that are similar but could be expressed in a slightly different manner from participant to participant. When all transcripts were coded, the researcher reviewed all nodes and sub nodes containing the now deconstructed data. The next step was to begin theme development or reconstruction of the data.

The reconstruction effort began as the researcher searched for those themes appearing across participants. Theme development crosses not only multiple participants but can include data across nodes and sub nodes. The theme development began by reflecting on the study aims, interview guide and any additional themes immerging from the probing questions asked to expand on the interview guide questions. The researcher continually referred back to Table 3 to ascertain which node/ sub node were related to which study aim. These identified nodes/ sub nodes were repeatedly the focus for theme

development representing each study aim. There was not a one to one ratio of themes to node/ sub node; more often it was a one theme to many node/ sub node combinations. Once all themes were identified another step was performed to refine the reconstruction even further. This step involved identifying four factors. Figure 2 represents the process of deconstruction and reconstruction of the data from raw data to factors.

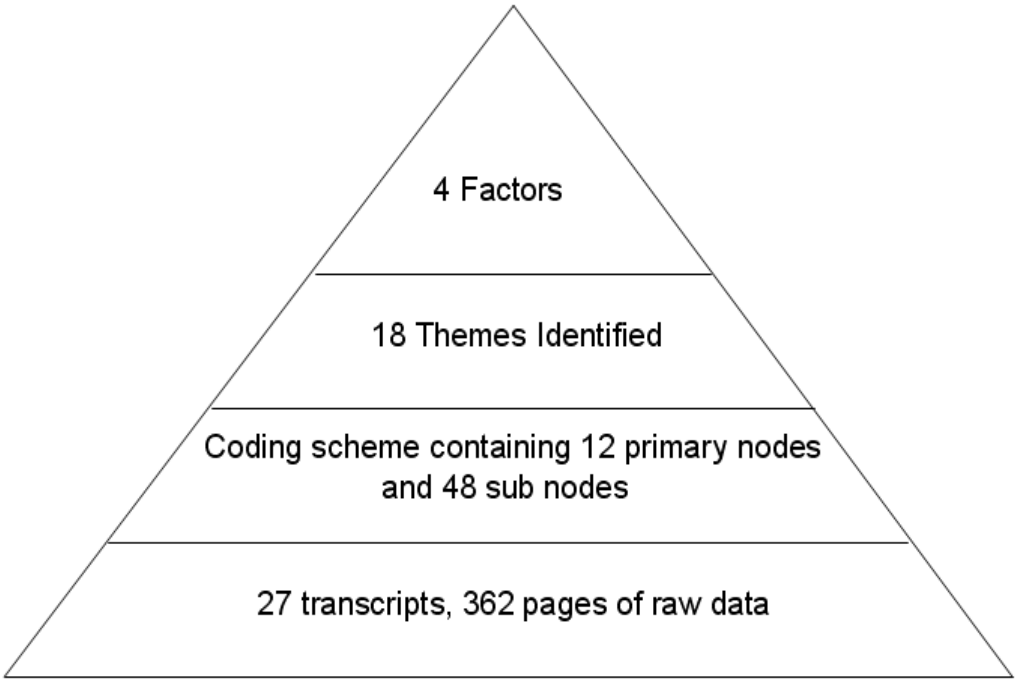

Figure 2: Qualitative data analysis process, deconstruction and reconstruction of data.

Once themes were identified, then exact quotations from the participant interviews were chosen which best represent the themes. The quotations were utilized in the findings to help the reader understand and accept the thematic structure proposed by this researcher. When all themes were identified from each study aim, the researcher looked for a larger structure, designated factors, which could include all themes within a few factors which directly reflect the purpose: to explore the factors which impact school

nursing care coordination for CSHCN. The results of the qualitative content analysis are presented to address each study aim.

Qualitative data analysis by study aim.

Study aim 1: Investigate school nurses understanding of care coordination and how they perceive their role in relationship to care coordination.

Several themes emerged from the analysis of the data related to study aim 1. These themes included: collaboration; overarching goals; parents lead the way; informal identification process; advocacy; liaison to the community; assessment is foundational; individualized planning. Each of these themes are described and illustrated with quotations from transcripts to support the theme.

Collaboration.

Collaboration is the process whereby the school nurse engages the expertise of many individuals within and outside the school for the benefit of the student. School nurses reported working with many individuals on behalf of the students they serve. They collaborate with various individuals to develop plans, to communicate plans and to manage plans for the care of the student. Some individuals who school nurses engaged were: parents, teachers, special education case managers, health office paraprofessionals, principals, psychologists, social workers, physical therapists, occupational therapists, public health professionals, health care providers, health educators, bus drivers, food service personnel, and special education assistants.

The school nurses frequently identified the parents as the collaborator whose input was most necessary and valued in care coordination.

> "I often say that it's a collaborative effort between me and the parents, because my plan may not be what the parents want so I, normally what I do, the process of that is to talk to the parents, and say, "here's what I am doing". Address each need, and talk about what's your vision for this, what's my vision, because sometimes you and the parents are completely on opposite corners."

Treatments and medications needed to ensure the health of CSHCN require authorization from parents and providers. School nurses contacted providers to obtain the necessary orders but also contacted providers when they observed changes in the child's condition which required medical attention or impacted school performance. School nurses found providers appreciated the effort to collaborate on care.

> "And what I find with physicians is that for the most part they get that. So, it's an easy . . . fix when you talk about the importance of education they're there. They're educated people. So, there are a few [physicians] that want to please the families and so they won't rock the boat. But for the most part if the kids are really, really starting to spiral down the physician is on board because they realize this just simply isn't working."

School nurses were in frequent contact with educators and paraprofessionals to collaborate care for students within the school building. Without these individuals' involvement, students would not receive the necessary care required to achieve identified educational goals. "I involve the teachers; I involve the administration so everybody is aware of what's happening with this child." The teachers and paraprofessionals have direct contact with the student and must be able to contact the nurse with questions or significant observations. School nurses described a level of comfort and belief in

collaboration with staff members; “Some of them will just so readily just call me up on the phone and say, “Let’s just talk about what plan of action we’re gonna … be doing with this particular student.”

School nurses have to consider collaboration with any individual within the school building who might need to provide care for a student. In an acute care setting nurses do not purposely seek out individuals such as bus drivers, playground monitors and cooks for collaboration. In the school setting these individuals might be the sole adult responsible for the child during a period of time, either during transportation to and from school, recess or during meal periods. Any student with a health concern might experience an emergency situation at any time and the school nurse is not always present. Therefore collaboration and communication becomes an essential piece in ensuring the care is well coordinated across all aspects of the education system. An example of care coordination with a bus company is provided.

> “We do have a student that has a transportation plan because of seizures and I am in the process of revising that and will coordinate with the bus company, when I make the revisions.”

School nurses work to collaborate with many individuals all for the benefit of the student. The school nurse collaborates to establish and achieve student goals.

Overarching goals.

Over and over again school nurses identified two primary goals for CSHCN. Simply stated these goals were 1) a good education “The whole goal; is to keep them in school and to make them successful.” and 2) safety “The goals for her are to provide a safe environment.”

These goals influence the plans school nurses make for CSHCN. The school nurse is able to participate in the educational team because other members of the team see the educational goals reflected in the school nurses care coordination efforts, whether in the written plan or in the one on one communication with the team and parents. Evidence of this understanding can be seen in the following two quotations:

> "It's more of a team approach, we just want their education to be the best we can for what the boundaries that we have to work with here within the disease process or the situation."
>
> "We really are looking for the success of their child and working towards that end."

The school nurse straddles both the educational and healthcare systems. Often the school nurse is the only person in a school building with a healthcare background. This can be an isolating situation but if the nurse continues to have the student goals focus primarily on school success and safety then school staff can support the plans made for meeting the healthcare needs of students. School personnel work closely with parents to identify student educational needs and goals.

Parents lead the way.

School nurses recognize the importance of engaging the parents in the healthcare decisions for their children, "I always allow parents to be in the driver's seat of making health decisions for their child." School nurses display respect for the parents by listening and developing plans based on the information shared.

> "I feel like working on that IHP together with the parents is a good start for that because they know that I've been listening, and understand their child's needs, and want to meet them."

When discussing who they approach to develop plans for students, one nurse stated, "[I'm] doing that in conjunction with most often the parent. I see the parent as being the focal point." By recognizing the authority of the parents both in the knowledge they hold about the needs of the student and the legal authority to provide information and approve plans, the school nurse becomes a partner in the planning for the student's healthcare needs but allows the parents to lead the way, supporting the parent in their role as care coordinators. School nurses must first identify students in need of care coordination. Parents often provide that first contact to inform the school nurse of their student's needs.

Informal identification process.

The first step in care coordination is the identification of those students whose healthcare needs are beyond those of their normal health peers. These would be students who might benefit from school nurse care coordination. School nurses described a variety of methods for identification starting with public health referrals following the birth of a child with a known chronic medical condition, early childhood intervention programs for children ages 0-3, preschool screenings before kindergarten entry, parent completed yearly health questionnaires, and school staff referrals.

> "Teachers identify students, our psychologists, and counselors identify students, just about, some community members, sometimes we get calls from a healthcare providers, by pediatricians, or family practice folks will let us know, but I'd say

> that most of them come either through our special ed team, through the building nurses, or parents."

and education team meetings.

> "One of the major ways is once a week we have what's called a student assistance team (SAT) meeting and that involves the school nurse in the building and myself as the district nurse, the school psychologist, the counselor in the building, the social worker at times sits in on that, and often times the principal if he has time. But this team sits down and meets once a week and teachers are able to refer student concerns to the SAT team and that's where we identify most of them."

Yet still some students are unidentified until there is an adverse event during the school day. "There are times that, ya know, we find out that a kid has pretty significant asthma when they come in from the playground and can't breathe and we didn't have a clue." Another nurse described her experience with a student just arriving at school in the following way:

> "Using my experience, again, I had nothing to really go on; this student came to our district. I can't even remember it's been, I guess I don't know where she was enrolled previous but totally came to our state into our district, so again you gotta hit the ground running just forming a plan of care knowing what you know about seizures."

In the end notification is a parental responsibility. "We would hope that the parent would connect with school nurse." The school district and school nurse provide multiple opportunities for the parents to provide notification to the school nurse. Until a student is identified the school nurse is not able to initiate any planning or care coordination

activities. School nurses utilize a variety of methods to identify CSHCN who require care coordination yet instances still occur when students are unknown to the school nurse and therefore cannot benefit from the care coordination opportunities the school nurse offers. As one nurse summarized, “I wouldn’t say that we have a really great system in place for, especially for identifying that care coordination piece.” Once a student is identified then the school nurse can begin advocating for the healthcare needs necessary for the student to be successful in school.

Advocacy.

School nurses identified themselves as advocates for students, parents, teachers and the district. The school nurse balances the needs of all these key players in pursuit of the student’s educational success. A primary function for the nurse as care coordinator is advocacy for the student.

> “Care coordination or my role as a nurse in the district, I feel like it’s such an opportunity for me to be an advocate for students. To provide them a voice sometimes where maybe… an issue isn’t being addressed elsewhere in their school day. So, I get to provide a voice for them to address a specific need and maybe raise an awareness of what that student might need to advocate for them. And I would say that would be the one thing that I would emphasis as my role in care coordination.”

Advocating for the parents ultimately impacts student success by supporting parents in the decisions they make on behalf of their children. “We hope we give them the resources. We hope we give them confidence, that they will be able to work with us

and the other community [members] and [the] team that works with their children [and] make really good choices for their children."

The school nurse understands the constraints teachers face in the classroom. As an advocate for teachers, school nurses develop plans for the healthcare needs that support the classroom teacher, reducing the impact of the healthcare needs of the student so the educational needs are primary. "I am doing frequently behind the scenes work so that the student's health care needs are not the predominant or [the] most visible need for the student during the school day." The school nurse also supports and advocates for teachers by providing the necessary information to the teacher so they are aware of the needs of the student and can accommodate the classroom for the student's needs.

> "It's also my responsibility to make sure that all the teachers that are involved with these students are aware that these kids have chronic health concerns so that their not blindsided when they're in the classroom."

Another school nurse participant offered:

> "[My job is] also to support teachers and staff in bringing information related to the students special health need be it like . . . diabetes, be it attention deficit, be it schizophrenia or bipolar disorder, to help educate staff and meeting that student's needs at school too."

Finally, the school nurse advocates for the school district and school district personnel. The school nurse is aware of the district legal requirements for provision of educational services. The school nurse also recognizes that the health and welfare of school district personnel can impact the success of all students in the district. School nurses have a role in the decision making process about district related health policies and

initiatives. “I see my role as, one, as a consultant to the non health staff in the district.” The school nurse as part of her role in the district also works with members of the community.

Liaison to the community.

School nurses are liaisons to community members on behalf of the student. In particular the school nurse collaborates with providers, public health system and state supported programs to understand and advocate for the needs of the student. “That’s where it’s really helpful to talk to the provider and the docs for the most part are very, very receptive when the school calls. They actually want to work with us.” School nurses reported they commonly seek out providers for input on the healthcare needs of the students. School nurses noted that it was the uncommon for providers to initiate the contact with school nurses on behalf of CSHCN. “In 19 years I have maybe had 2 physicians contact me. I generally will contact them and then of course it’s their nurse that communicates with me from area clinics.”

Liaison with providers might be common but school nurses also seek to liaise with the county public health department and the state. “We do contact the county if we need to and ask them for help. Then also the Minnesota Special Needs lady, like say somebody needs financial. We had somebody; we have quite a few that are Spanish speaking. Some of the kids are only Spanish speaking, very limited English.” The school nurses collect information from providers and seek out additional information as they assess the needs of the student in the educational setting.

Assessment is foundational.

The school nurses identified assessment as a key function of the care coordination role. "As a coordinator of care I have been responsible to assess the student." Once the assessment is complete and the school nurse understands what the needs of the student are then planning can begin.

> "One of my primary roles is to understand what their health needs are to make that assessment. And then, understand how that will impact them in their classroom, and what then would be needed in terms of accommodations."

The school nurses identify assessment as a foundational step to all the other steps in care coordination. "I would say my role would be to identify first and foremost what are the student's needs and then set up goals to provide support for those needs, and then in addition to that to be a resource to staff and families." As a resource to the family and staff the school nurse educates these individuals on the findings of the assessment and helps the staff and the student understand the plan resulting from the assessment.

> "I view myself in a lot of situations; the educator . . . kind of, educate[s] not only the child but the teachers or whoever the staff members that are working them are, so that they know exactly what's going on."

Once the assessment is complete, the school nurse can begin the planning process. Because of the unique problems faced by each CSHCN, school nurses work with the appropriate resources to develop plans for the individual needs of the student.

Individualized planning.

A large portion of care coordination is developing a plan for the individual needs

of the student. The school nurse recognizes this need for the student and for the individuals managing the plan created by the school nurse. School nurses delegate tasks related to the care plan to individuals who might not have a healthcare background. The school nurse must establish a plan that meets not only the needs of the student but the needs of these untrained providers of the health plans needed to keep the student safe and successful in school. First and foremost the individual needs of the student are reflected in an individualized healthcare or emergency care plan. School nurses describe this effort as follows:

> "What I have on one student with a tube feeding, and what I have for another student with a tube feeding might be very different because I will put in there that this student prefers this or dislikes this or you need to do it this way or whatever."

Another school nurse participant offered:

> "When I put a care plan together I look at, I try and look at every aspect of the child's life, and how what I do at school is going to affect them at home. What's happening at home is going to effect that child and so I try to get all those meshed together into one care plan."

Another school nurse participant offered:

> "That's why I say every plan is gonna be different, some parents, if their child had any seizure would want 911 called, some they see so often that it's like okay wait three minutes, five minutes before you give the Diastat and then only if that doesn't work after 10 minutes call 911."

As previously described, school nurses collaborate with many individuals within the school to manage and perform tasks identified within the healthcare plans. For

individuals untrained in healthcare, plans must be written in a manner they can understand and respond to. Examples of statements supporting this need are presented.

> "The transportation for example the transportation those are actually [I] write a separate care plan. I found that for them to follow the school care plan wasn't, there's just too much information. They needed a much simpler directions about what to recognize for seizure for example, and what to do about it."

Another school nurse participant offered:

> "You're trying to put it in, you're doing it for teachers, you're doing it for EAs [educational assistants], so you know sometimes it's like what you might see, you know, and then actions. I mean so there might be pretty more, you know, pretty basic because you wanna make it so someone not medical is following it."

Another school nurse participant offered:

> "In the early part of my nursing I tried doing that with goals and all sorts of wording and explanation and everything. And they just aren't read. They are pretty much useless because teachers don't have time for that, especially if there is more then one plan they need to be looking though at the beginning of the school year, which is very busy. So, we have made them much more simple. So that they are read and they are understood and teachers know what to do and where to send the child if there is a problem."

During the interview process in response to some of the comments cited above, one question was added into the interview guide regarding the use of standardized nursing terminologies. Some nurses had mentioned that they incorporate nursing diagnosis, interventions and outcomes in the plans created for themselves or other school

nurses, but as described above, the school nurses noted that plans needed to be written in basic terms to be understood by non-nursing personnel. Typically the school nurses wrote in a less formal manner in order for the plans to be useful to teacher and support personnel. Examples of this finding are presented.

> "And that's one thing in school nursing you have to use layman's terms because you have teachers and paraprofessionals reading this care plan."

Another school nurse participant offered:

> "Using that NIC, NOC, NANDA diagnosis, intervention, outcome; it is in nursing speak; it's not in layman's terms. So, an educator or paraprofessional may not understand it."

Another school nurse participant offered:

> ". . . the nursing diagnosis formats. And I have not embraced that. I try to make my care plan easy for the people that need to use them. So, and those are teacher people not nursing people necessarily."

School nurses acknowledged that the needs of the student change over time and do not necessarily follow a predictable course. Therefore, individualized plans need to be reviewed and revised based on the current needs of the student. These plans then can follow the student from grade to grade and school to school.

> "If a health plan is developed and needed that health plan is followed and reevaluated, it follows with the student as they go through their academic career, and it's reevaluated and tweaked as needed. As we, you know, as we move through their development."

Eight themes arose from the analysis of the interview data to determine themes describing school nurses understanding of care coordination and their role and responsibilities in care coordination. The themes of collaboration, overarching goals, parents lead the way, informal identification process, advocacy, liaison to the community, assessment is foundational, and individualized planning have been described and examples from transcripts have been provided to support the themes.

Study Aim 2: Describe tools/ resources used for planning care coordination activities.

Two themes emerged from the analysis of the data related to study aim 2. These themes were information resources and seeking evidence. Both of these themes are described and illustrated with quotations from transcripts to support the theme.

Information resources.

The school nurses described resources they utilized for gathering information as part of the process of planning for care coordination. The school nurses sought information from publications, electronic media, colleagues and parents.

Published resources identified by school nurses were textbooks, handouts, manuals, and journals. In particular many of the school nurses identified a book on individualized healthcare plans as a useful resource. “I have a couple books that I kind of really become my bible as far as a couple books from Individualized Healthcare Plans for School Nurses. And that’s a wonderful resource.”

Another school nurse participant offered:

> "The Sunrise Press nursing care plans have been a great help as a new nurse especially. I utilized many of those, different [ones], for seizure disorder, for constipation; whatever . . . that was a really good resource."

One concern expressed by the school nurses was the currency of information in the published format. As one nurse expressed her concern, "Books become obsolete pretty quickly." The school nurses would need additional resources if they want to assure the information they utilize is current. One means of addressing this concern is utilization of electronic resources.

The school nurses indicated they utilized electronic resources especially the internet and the School Nurses of Minnesota listserve and website. The nurses indicated they thoughtfully selected internet websites as a resource based on the credibility of the site. Some credible sites named were: Mayo Clinic; American Association of Pediatrics; Centers for Disease Control and Prevention; American Association of Family Practice; National Association of School Nurses; Minnesota Department of Education or Health; WebMD; American Diabetes Association; Food and Allergy Network; Epilepsy Foundation; National Institutes of Health; and Wikipedia.

> "I try to be as accurate as I can be when I am evaluating something but as far as the information I get I feel the sources that I'm using, I try to find credible sources that have a history of being credible. And their answers are based on research and some of these fly by night sites you don't know for sure what their basing their information on. I might go to the Mayo site or sometimes some of our manuals have websites too."

Another school nurse participant offered:

> "I will use a lot of the search engines to find tools and resources online. You just have to be careful that you're getting a reputable source. But that's usually not too hard to find. You can usually find really good resources for information online. And it's often, you know, very up to date. So we use our online resources often."

Another school nurse participant offered:

> "I use the internet as needed, Mayo Clinic, or the different affiliated websites, or NASN to get information right from their sites because I trust that and want to utilize that first."

Another reason school nurses utilized electronic resources was the ease of use. Nearly all the school nurses reported they currently had access to the internet.

> "And [it is] much easier than it used to be. When I started school nursing we didn't, back when I started we didn't have the internet available to us. And just to try and find information, manage all that information, and keep track of it you'd have to print things up."

In addition to published and electronic resources, school nurses contacted other healthcare professionals or other school colleagues to provide information when developing care coordination plans.

Other school nurses and physicians were resources utilized by school nurses for planning care coordination activities. Other licensed school nurses either within the same district, within the region of the state of on the SNOM listserve were the frequently cited as useful resources. One nurse who had recently become a school nurse reported "using other licensed school nurses who have, again probably more [experience]. Again, I am one of the newer comers as a licensed school nurse so I turn to them who had maybe been

in this position and had been there and done that."

Even experienced school nurses sought out other school nurse for ideas. Sometimes the contact was in formal meetings, "We meet with our regional nurses quarterly and I find that helpful in hearing about what other nurses are doing and using as ideas that I can look into more." Sometimes the school nurse will seek out a resource for a particular concern, "I can call other school nurses which is helpful, especially school nurses that have been in the district for a while or had quite an extensive history in school nursing."

Physicians were identified as another resource. Some school nurses have an established relationship with a medical provider, "we have one doctor in town that is our medical advisor." and others contact the physician or their representative on an as needed basis. The school nurses reported that physicians were generally willing to talk to them and were supportive.

> "Our local pediatricians are very supportive and I think in that sense the smaller community is definitely helpful because they're well connected to their patients and invested the school and so they're very ready to help us to problem solve."

Parents were identified as key informants for planning care coordination activities in the school. " Actually it's the parent that I feel [are the best source of information]. It's one of the most valuable resources to me about care of their child. Especially, children with special health needs, they know their children." and "I would say many other times [for] the special healthcare needs that it's the family of the student or the group home nursing staff that give[s] us most of what we need."

Parents choose to provide information, as much or as little as they see fit and without their permission, school nurses were limited in the amount of information they could obtain from other healthcare providers." I think in regard to families, I think there is also a control thing. That they just wanna be in control of what information we get." or "Some parents don't want to share much information and others want everyone to know everything." The school nurses reported they obtain written permission to contact providers or to request records and abide by Health Insurance Portability and Accountability Act (HIPAA) regulations in regard to sharing of information.

In general the school nurses believed the parents provide fairly complete and accurate information. "It seems like parents are very helpful in giving fairly good accurate information. And the medical records are good too, but a lot of times, the medical records base their information on what they have gotten from the parents, too." Some exceptions were noted. The school nurses attributed the lack of completeness or accuracy to a lack of understanding "The doctor or nurse has explained something to them and whatever they understand or what ever they retain is what they bring back to school." or due to language or cultural barriers. "I think parents from different backgrounds or struggling with other issues, sometimes then it's harder to get accurate information."

There were a number of resources identified which school nurses access when planning care coordination. The school nurses also identified a need for more evidence based resources.

Seeking evidence.

The school nurses described a number of resources they used for information

needed to plan care coordination. Additionally the school nurses were interested in evidence for their planning rather than just what they think is the best method. “I love to see things in place, evidence based things that have worked well . . . and [were] researched. I would love to see more of that, and I would love to see nurses using . . . evidence based practice guidelines more . . . I don’t see right now.”

They were interested in recommendations which were grounded in research, especially research which supports positive outcomes from school nursing care.

> “But are we doing it the best way and then, that’s where I’d like to see more use of research and then in our whole district and . . . the nurses more evidence why am I doing this. I am just sort of rotely doing it or just automatically. I’d love to see . . . are we doing it correctly and what are the outcomes of what we’re doing, and is it correct? We’re just starting to talk about that. So, I would like to see that to help me do my job better.”

School nurses were resourceful in obtaining the information necessary for planning care coordination needs. They used both printed materials and electronic media for information in planning care coordination needs for CSHCN. They reached out to other school nurses, physicians, and parents as additional resources. In selecting resources the school nurses were interested in credible, evidenced based information which could support positive outcomes for the students they serve. Once school nurses compile this information they can begin planning for the care coordination needs of their students.

Study Aim 3: Describe the systematic process used for planning and communicating care coordination activities.

Three themes emerged from the analysis of the data related to study aim 3. The themes identified were: individualized care plans, templates for plans, and individualized communication process. Each of these themes are described and illustrated with quotations from transcripts to support the theme.

Individualized care plans.

All the school nurses interviewed described types of written care plans that were individualized based on the needs of the student. The school nurses indicated they might develop either Individualized Healthcare Plans (IHPs) or Emergency Care Plans (ECPs). "We developed an emergency care plan for those two concerns and then we had an individual health plan that looked more, overall, at her goals we wanted for the whole school year." Some of the school nurses indicated that the plans were most likely to take the format of an emergency care plan. "I would say our care plans are mostly emergency treatment type of care plans, procedural." The ECPs were written for students who might have a life threatening emergency where staff other than the school nurse would need to be prepared to handle. The procedure embedded in the ECP includes step by step directions for the emergency care required for the student. There was enough information included in the ECP for the staff member to initiate proper care until the emergency responders or school nurse arrived to assume responsibility for care.

Consistently the nurses reported that plans were reviewed and revised. "I always do new plans at the beginning of every year." There was less consistency in the

notification of parents of the plan. Most nurses reviewed the plan with the parents; it might be during a meeting, by phone or mailing a written copy. "We do attempt to ask our parents to sign off, it doesn't always happen. Sometimes . . . we'll get verbal consent or a telephone consent." School nurse were inconsistent in their reporting of a systematic process for obtaining a signature on these plans from parents.

> "As you can see I have no signature. Because typically I will send them home and they will not come back. But I at least make an attempt for the parent to [sign it] …Whenever I do a new care plan, I tell the parent look it over, if there's any thing that you don't agree with let me know and I will change it so that we're all on the same page."

In the instance described above, the plan might be reviewed and altered based on parent feedback but the school nurse is relying on the parent to contact the school nurse if changes are needed.

Other nurses send out a plan but do not expect a signed copy to be returned. The school nurse does however expect a response from the parent if changes are required.

> "Families review them always. They don't sign off but they review them always. They review them then they send them back to me. Then I tweak them if there's any mistakes made or if they want anything added. And then I'll send them back to them and they'll say looks good, and then they get a copy as well and then I'll just document on their chart, health plan reviewed by parent no changes necessary or changed to meet student needs or whatever."

The school nurses interviewed were able to describe varying types of healthcare plans developed for CSHCN in their schools. School nurses also identified that they

utilized templates of plans which might be adapted to the individual needs of the student.

Templates for plans.

Repeatedly, the school nurses reported they used IHPs which had been developed by reputable organizations. In particular the school nurses reported using plans for severe food allergies which had been developed by the Food and Allergy Network, and seizure disorder plans developed by the Epilepsy Foundation.

> "[I] especially [use] the Food Allergy and Anaphylaxis forms we have, the district leadership has taken a look at those and kind of modified them for our purposes. So, I would say yes, we use them but we kind of modify and logo it for ourselves, and same with the Epilepsy Foundation."

School nurses face a variety of health conditions which might need care coordination and planning. Standardized plans are not available for all conditions so some of the school nurses individually or within their district developed an individualized healthcare plan template which could be adapted for many health concerns. "I suppose through the years I have developed my own system of care plans for children with special health needs but no there's no templates our particular computer program has." The school nurses indicated that plans are written with the reader in mind.

> "For problems that we don't routinely deal with, like the example that I had given before, we have a standard care plan where you have the demographic information on the top, and then you have a section where it says . . . look for this, and then it is what to do in the second column. And it is made to be really simple because teachers do not like complex plans."

Another school nurse stated, “We have forms available online, that we can customize, so yes, emergency care plans, individual health plans for some of the more common health needs.”

School nurses used a variety of strategies to use or create templates to standardize the care they provided. Once plans are created the school nurses described a variety of process for sharing and communicating the contents of the plans.

Individualized communication process.

Once the plan is written, the school nurse communicated with the staff members responsible for the student. This communication process was individualized based on the needs of the student, the staff and the school nurse. School nurses utilized various methods to communicate to school staff the plans which were in place for individual students. There were three approaches most commonly cited as a communication method. School nurses might provide a copy of the written plan to the staff members on a need to know basis. Another common method was a one on one education and demonstration of the plan to the school staff members responsible for implementing the plan. Finally electronic communication through a computerized student record system or by e-mail was described.

Written communication took the form of paper copies of the plans sent directly to staff. **“**It’s still old fashioned but it’s the paper copies. Printing out the care plans and giving the copies to the people that are part of the student’s team.” Some school nurses expressed concern that these paper copies of plans were vulnerable to breach of confidentiality. “We have not sent [out] plans to the individual teachers. The problem that runs into that is again student confidentiality, and if it would be left out on a desk or

another student would see it becomes a problem." To control for breach of confidentiality, some school nurses place lists of students' significant health conditions in a folder or binder in a controlled area of the school and allow school staff to review them in one location.

> "At each secretaries desk they have a red notebook and in there I've put the sixth grade, the names and what kind of a problems that they have, like it's asthmatic or diabetic, just simple. And I just do that by grade so the teachers know that that's there and so, if there's a sixth grade teacher or they have sixth grades students I tell them . . . to go in at the beginning of the year, sometime during the year and make sure that they look. So, that they know which ones of their students are having significant health needs."

Any questions regarding details of the care plan then require the teacher to approach the school nurse for review of the care plan. The school nurses reported working directly with school staff to train or educate them on care plans for specific students or on general care for specific disease states. The focus of training was not just teachers but many of the ancillary staff in the school building.

> "Building nurses will communicate directly with teachers and ancillary staff, the plans. I also do trainings. I do a lot of trainings every year. I train bus drivers, and support staff, paraprofessionals. I try to get to cafeteria and the playground folks."

Another school nurse participant offered:

> "The parent, say it's the fall of the year and we're just starting school, maybe the workshop week the parent might come in and we'll schedule off time to meet with the teacher and talk about his plan."

Another school nurse participant offered:

> "So, often times we'll have a little gathering of the people at that are working with that child and have a little teaching session. Whether it's how to use the Diastat, or if they have an Epipen, or what to do if they have a seizure, so I'll meet with those people and we'll have review the care plan but also do some teaching. And the other thing that we've done the last couple of years is actually done that mini first aid sort of training at the beginning of the year for all teachers and all staff. Just because we know of ten people that have emergency care plans but you never know when a kid's gonna have a first seizure or you know so we actually do some seizure, first aid, diabetic, allergy, and Epipen kind of training for everyone just so they're aware of if some sort of symptom happens that might something they think about and call for help."

Additionally school nurses utilized electronic communication through the student information system or through e-mail. School nurses reported having access to a computerized student information system. The types of systems varied as did the functional capability of each system. Some of the school nurses were fully utilizing all the functions available to them and some were utilizing only basic functions like demographic data collection. Some of the systems offered the school nurses opportunities to provide alerts to teachers regarding students in their classrooms.

> "We're fairly new with the system and so we flag a student that will have a healthcare plan so that their teacher knows to look for a healthcare plan. And so we list if there's any, they may have a medical condition but not have a healthcare plan. We'll flag that as well. So, that would be specific to that teacher only that would get that information."

Other systems might alert the teacher and provide direction on management of a health condition identified.

> "Our computer system has an alert on it so that student's name would come up in red and the teacher will see their names in red and click on it, and it will say "fainting spells, call the health office if the child faints", something like that."

Some nurses sent out complete plans by e-mail to the staff directly in contact with the CSHCN. The amount of information contained in the plan could be easily modified based on the school staff member receiving the e-mail.

> "I will usually attach via e-mail the plans that I need to specific people. For my, our food service type of people that there is a life threatening food allergy list and that sort of thing, I just send them an Excel spread sheet on that."

The school nurse might utilize e-mail in combination with a paper copy of the healthcare plans and a face to face conversation.

> "Via e-mail, I just alert them that this student has a special health need and that a care plan will be in their mail box in a sealed envelope for them to read and then put in their sub file and then if they have any questions they need to come and see me. That's basically it. It's electronic communication."

School nurses had a number of methods identified for planning and communicating the care coordination plans for students. They reported the creation of written care plans, either IHPs or ECPs. They reported seeking out templates from expert organizations and individualizing them for their students or district. School nurses reported having a template of healthcare plans for less common medical concerns. School nurses did communicate plans with parents and school staff. The school nurses consistently reviewed plans on a regular basis and integrated changes into the plans as the student's status changed. These plans, once complete, were provided to staff on a need to know basis in as much detail as was needed based on the role of the staff member and the level of responsibility the staff member had for the care of the student.

Study Aim 4: Describe the impact of helping relationships on planning and communicating care coordination activities.

The school nurses in this study had strong opinions about the impact of helping relationships on their ability to plan and communicate care coordination activities. During the interview only one question was devoted to this topic. Many of the school nurses asked for a definition of helping relationships. They reported they were unfamiliar with the term. A definition was provided for the school nurses who were unfamiliar with the concept which was defined as those relationships developed for the purpose of aiding another person to achieve their goals; the school nurse does not personally benefit from the relationship. With this definition in mind, the school nurses provided responses which were analyzed for themes.

Two themes emerged from the analysis of the data related to study aim 4. The themes identified to describe the impact of helping relationships on planning and

communicating care coordination activities were: essential to success; trust. Both of these themes are described and illustrated with quotations from transcripts to support the theme.

(Helping relationships are) essential to success.

Many of the school nurses described helping relationships with parents, students and staff were essential to the success of planning and communicating of care coordination activities. The school nurses recognized that the cooperation of the family was a key component of planning. “I think it plays a huge role. If you are [not] able to develop a good rapport with the family and the student anything that you plan or try to do with the family is gonna be more difficult.” Another nurse identified the need to engage the parents in order to obtain information from healthcare providers needed to make appropriate plans at school.

> “I think if you establish . . . helping relationship it’s just huge for getting what we need at school, to accomplish at school. And get all of the information from the healthcare providers, etc. . . . I always try to let the parent know that I am their child’s advocate and their advocate as well. And so, and then I’ll do all I can to work with them and that they are as vital to how successful their student is at school as that health care plan is. So, I think it’s really, really important.”

School nurses also develop helping relationships directly with students. The relationships are developed for the purpose of achieving the previously identified overarching goals of school success and safety. If parents understand that this purpose, school success in a safe environment then they will more willingly work with staff and make decisions that might be tough but are in the best interest of the child.

> "You always have the student in the middle and that's the person that we're helping in that relationship. Or helping a parent understand why this plan would be good for their student, especially those who are hesitant about the special education label, or hesitant about considering medication if that might be indicated, or when I'm in those sort of meetings that there's some sort of, I don't know what the word is, hesitancy or just defensiveness because they don't wanna hear what might be the plan. If we always bring it back to what's best for the child and how they'll succeed I think that makes it easier. That makes it easier for me, so in terms of this helping relationship that would be the best way to do it. You know, your purpose is to help the student achieve and so what do the 6, or 8, or 10 people around the table need to be doing to move in that direction."

Another school nurse participant offered:

> "[I] would say it's essential, essential. We need to establish very good relationships with the students . . . they feel safe coming to us, and sharing information that we need. And then of course the other relationship that's essential is with the parent. I am always reminding my staff that we are health services and the parents are the parents. We are not the parents of these children. The parents are the parents of these children and as such they trump. They are our trump card. So, it's very important that we communicate well with parents, that we establish good relationships with parents, and that they trust us, and that we empower them to make really good decisions for their children."

Part of developing a helping relationship is familiarizing the parents with the school nurse. The parent must have confidence in the ability of the school nurse to care

for their student. The parents also need to understand the school nurse's dedication to their students and they will be willing to listen and learn from the parents.

> "I think that that piece is essential in how effective I can be as the assistant in the coordination of care. Because they feel like without them knowing, I mean it has to do with them getting to know my style, and my knowledge base, and my ability manage, or understand the health condition but I think also my investment in their child and they think, I hope that families that I work with understand that my message and my goal is that helping relationship with them is that I believe that their current health status doesn't need to prevent them from learning and that their ability to learn as . . . the learning that takes place in the classroom is gonna be key to managing the health condition for all of their life."

The school nurses also identified the negative consequences of not establishing a good relationship with the families.

> "I think it's just a critical piece that you have the guardian of the student you're working with on board. I just think to negate that or neglect that would be like shutting a door on [a chance for success]. Because if everyone's on the same page and if that parent or guardian feels good about what you're doing and feels like they're included they're gonna buy into, they're gonna be more apt to, they're just gonna be more apt to follow along and to go with it if they feel part of they're, they're part of the plan it just makes natural sense to me."

Additionally, if the school nurse and the family do not have a relationship where the parents are at ease with contacting the school nurse then there is a chance that the school nurse might miss an opportunity to plan for care. Identification of the student

might also be missed. “Because if you don’t have that to start with there’s not going to be any of those things and there’re possibilities of things falling through the cracks.” Falling through the cracks might mean lack of identification of the student, or the student needs or follow through on the identified needs might be missed.

The school nurse does not work in a vacuum. The school nurse is part of the educational team and part of a community. Helping relationships with school staff go beyond concern for the students needs. Sometimes the helping relationships with school staff are for the purpose of helping the staff. “I would say I’ve also used that helping relationship with staff. I feel like I’ve had staff contact me outside of school hours or even during school hours about concerns that they may have, and they look to me as a resource for their healthcare needs. And so, I would say in that way yes, I would say helping relationship is a key part of my role.”

The school nurses indicated that they develop helping relationships. In order to develop a helping relationship the nurse must first establish trust.

Trust.

The school nurses repeatedly mentioned the theme of trust. Even more essential than helping relationships, trust was described by one school nurses as, “a good trusting relationship with parent[s] is an absolute must.” Over and over again the theme of trust was highlighted by the school nurses in this study. There were various aspects to trust the school nurses identified.

One aspect of trust was the ability of the families to let go of control of the care of their special needs child to anyone other than themselves.

> "It's especially important with families because they're especially with the elementary age kids they're so protective of their kids . . . and they're fearful too. This is one of your most precious things in your life and you're sending it off to be taken care [of] by someone else, and your child has something that's not like other kids. So, there's some fear there and some concern. And so developing a good relationship with the parents so that they know that they can trust you and they know that you're knowledgeable and that they know that you're really looking out for their child is really important."

Another school nurse participant offered:

> "I remember a particular student that has since passed away, and the parent said when she first came [to the school], they said "We're trusting you with our baby. She is only three years old." And I just remember that it's like "here she is here's our gift". And just really, that was a leap of faith for them to the point where we still, we laughed about it with them but they would literally hide on the playground and look in the windows. They really struggled to let go and she died as a result of her ongoing health concerns but by the end they said we couldn't have imagined that it would be this great and what a gift you guys were to our little girl in her short life."

The school nurse must be an image of professionalism so that parents can trust in the school nurses ability to provide appropriate care, perform those treatments or tasks that are essential to the health of the child. Additionally the parents need to trust in the school nurse as an advocate for their child. The families might be in conflict with teachers or the school district but they trust the school nurse will always place the needs

of the CSHCN first and foremost. “I think those families, there’s a certain level of trust that develops when you’re able to establish a good relationship and they trust that you have their child’s best interest in mind. The coordination is much more difficult when families don’t trust you or they view the school district as kind of an enemy.”

Establishing a trust relationship takes time. The relationship with the family might start off lacking trust but over time and with persistence on the part of the school nurse trust can flourish. One nurse describes how she was able to be successful providing care coordination to one CSHCN as, “After gaining the family’s trust, it’s been four years now that she has been under my care here, with her and [I have] seen many good changes.” Another nurse noted the lengthy time it took to develop a trust relationship with one mother, “I would say it took a good year, year and a half to finally get her to trust me.” Once the trust relationship is in place then school nurses identify that care coordination is facilitated because they have access to information that families previously did not share. This school nurse anticipates the positive results that will be evident once trust is in place.

> “[I] look forward to building that trust . . . how they allow you in to that very protective maybe circle for their child of people who they allow, [who] they give information to and allow to be thinking about how [that] plays out in real life.”

The trust relationship is important with students as well as with families. When students trust the school nurse they are able to talk about and share concerns that are impacting their education. Then the school nurse is able to take that information and develop a plan to help the student.

> "Once you present it that way [that you are interesting in helping them] kids do really, really well with that and the more they trust you, the more they give, and the more I get in terms of information, the more I can assist them."

Staff members also need to trust the school nurse. Staff members have direct contact with students and therefore have access to information on the functioning of the student that the school nurse might need for planning or evaluating care coordination activities. Without the staff members trust, the school nurse might not receive this information. "It's huge because trust is the basic premise behind students and staff being willing to talk to you." If students or staff members fail to talk to the nurse when concerns arise then care coordination is not optimized for the needs of the CSHCN.

A helping relationship might be developed with a student, a parent or family member or a school staff member. One theme developed around the concept of helping relationships is that helping relationships are essential to the successful planning and communicating of care coordination activities. Without first developing the helping relationship, care coordination is more difficult to accomplish. Trust needs to be established before the school nurse enters into a helping relationship. Trust between the school nurse, families, the student and staff is important. Once trust is built between these individuals then the school nurse will be more successful in establishing the helping relationship needed to plan for and communicate the care coordination plans for CSHCN.

Study aim 5: Identify factors associated with facilitating care coordination activities.

Two themes emerged from the analysis of the data related to study aim 5. These themes were communication and support from the team. Both of these themes are described and illustrated with quotations from transcripts to support the themes.

Communication.

When asked to identify a factor which facilitates care coordination, one school nurse answered this question very concisely "communication is essential". Communication assisted the school nurse to develop, manage, evaluate and communicate care coordination activities for CSHCN. The ability to have good communication is important because there are so many individuals involved within the school, the family and the community who all have an interest in the success of the child at school.

> "I think the biggest thing is communication between the people that are involved in the care. And setting out a direct thing to follow; a time line and like an agenda, and what needs to be done, and how it needs to be done, that kind of thing."

Another school nurse participant offered:

> "Certainly what facilitates it is good communication. Always facilitates it, whether that's . . . with the educators and the support staff [or] within the school district."

The ability to collect the needed information in order to plan for care coordination relies on good communication between the school nurse, the families and the healthcare providers. In order for the school nurse to communicate with healthcare providers, the

school nurse must comply with regulations and obtain written permission from the parents to contact the healthcare provider. This is not always an easy task for the school nurse. School nurses did recognize that obtaining information is a critical piece in providing care coordination activities for CSHCN. The availability of permission or lack there of could be both a facilitator and inhibitor of care coordination activities. “It’s facilitated if the families will get those releases all signed at the hospital and send them all back to us or whatever from the doc.” and “Clear communication with a family who is open to a release of information so you can contact and get really good direct information is helpful.”

One school nurse summed up both themes in this one statement, communication between interested parties and working together as a team.

> “I think the things that really promote it [care coordination] are that open relationship and willingness of families, to work with the healthcare providers and, as a healthcare at school I should say, and giving us the okay and the releases of information to contact healthcare providers and that type of thing. That really has been, that’s such a positive thing and … I’m very fortunate because we have a lot . . . [of] people who really have understood the importance of the healthcare in school.”

School nurses, even though they might be the lone healthcare provider in the school or the district, recognized the importance of being part of a team, being accepted by the team and the support of the team. School nurses recognized that without the support of the team they would not be able to provide the care coordination needed in the educational system.

Support of a team.

Care coordination requires a team of people working together to address the healthcare needs of an individual. Like a well oiled machine, a team working together is more efficient and successful in achieving the sought after goal. Even when disagreements arise, the team can resolve differences in a respectful manner. The team supports the goals for the student and not a personal agenda.

> "I think factors that facilitate care coordination is I work with an excellent team of people that are willing to work together and listen to each other. As well as be able to disagree without conflict occurring. And I think that makes for good team harmony and the student benefits in the end."

Another aspect of team support is the mutual respect among the team members. The school nurses perceived respect from the district and other members of the team working for the student's success.

> "I would say there's a huge respect for us in this district as nurses. I think there's a strong support system in place for us. So, there's that professional respect which I think is real helpful. I have never felt like a second class employee or second class professional in the school district. We may not understand one another's language but there's definitely a respect and a professional respect, which I think can facilitate that relationship."

Sometimes there are clearly defined teams. Teams related to special education planning have a formal role defined by the school or district. School nurses are often members of these teams and find support amongst the members of those teams.

> "Certainly the things that are beneficial are that entire [student assistance team] SAT team; all of those resources and that team work seem[s] to be beneficial."

Teams can also be informal. School staff members are a team within the school or district where they serve. School nurses see the support of staff members as important because this support allows the nurse to be a more effective team member.

> "Having a staff that's supportive and believes in you is also very beneficial because they will come to you if they feel that you are effective and the more comfortable they are with you and the more effective you are the more they come to you."

Two themes emerged that are interconnected and essential to the facilitation of care coordination; communication and support of a team involving the school nurse. Communication might occur between the school nurse, school staff members, the families and healthcare providers. All the individuals identified as necessary for communication are part of formal or informal teams that supports the school nurse in care coordination.

Study aim 6: Identify factors which inhibit care coordination activities.

Barriers exist to effectively provide care coordination. Two themes emerged from the analysis of the data related to study aim 6; time and access to information. Both of these themes is described and illustrated with quotations from transcripts to support the theme.

Time.

The school nurse identified time or lack there of as a major inhibitor to providing

care coordination activities for CSHCN. Many of the nurses work in multiple school buildings. Available time to coordinate care is impacted by the lack of presence in the building when concerns arise. “I find that to be, especially with three schools, to be very, very difficult, to do a good job.” Not only the number of buildings but the sheer numbers of students impinge on the time available for the school nurse to provide care coordination.

> “There are so many students and so many student with health issues that you have to divide your time up so many ways to try and reach all the students that you need to reach and pretty much go with your critical and your middle of the road [students] and then those that they maybe are not as emergent to care for but time is a big factor. And then a lot of …duties fall on the school nurse stretch the time even further.”

With the time demands of multiple schools and many students, the school nurses identified creative ways to meet these needs. Some school nurses took it upon themselves to work during their off hours just to keep up with the demands of providing care coordination for CSHCN. “You know, I work I would say probably 3 out of 5 evenings a week and then on the weekends.” Formulas for managing time at the beginning of the school year need to be adapted based on the reality of the required needs of the students. “I’m definitely stretched. I try to use a formula in the beginning of the year based on population and numbers about how much time in each building but of course that changes with kids’ needs and as things happen.” Outside of working on off hours and readjusting formulas for time management school nurses identified that they sometimes had to compromise on the standard of care coordination provided to CSHCN.

"In the rush of time and things that might not be getting done as much as nurses, you know, realize and should do."

Another school nurse specified how lack of time impacts her output in care plans.

> "More then anything time is probably the hardest thing. I try to make my, all my care plans, they all have nursing diagnosis, they all have goals, objectives, and interventions. And, sometimes I might limit how many I might put in there, if I have the time I might get a little wordy. But time might be the biggest factor for me, but still everybody gets a pretty good care plan."

Other aspects beyond care coordination are impacted by lack of time. School nursing care for the entire population of students might be impacted. "And then we try to bring in the other wonderful things that we as school nurses would always like to be involved in. But those are things that time wise is impossible to do." As another school nurse stated, "It all takes time and when you really only have two hours in each building sometimes it's not as one would wish it would be." Summing up the theme of time, or lack there of, one school nurse stated, "There is never enough time to do everything." Even though school nurses were interested in doing everything, the reality is time limits what can be accomplished. Accessing information is an important part of planning for care coordination. This is not always easy to accomplish and takes time. Access to information was the second theme identified as an inhibitor to care coordination for CSHCN.

Access to information.

Information is essential to the development of plans for care coordination. Conversely lack of access to information can result in frustration for the nurse and possibly unsafe situations for the student. One school nurse expressed these concerns as follows:

> "I think . . . for me one of the more frustrating pieces with care coordination is you really are at the mercy of the parents. Because they have to share with you what is happening with their child and I'm type A enough that I really want to know what's going on in my building. But I really rely on parents to be able to give me that information. And some are wonderful and some are like they give you more information then you'll ever really need, but there's a lot of people that just assume that you'll know or you'll figure it out. And it's a lot of holes and it's also it's not always a very safe way to practice. So, we do the very best we can give what we have to work with. . . . it would not be accurate if I told you that I am totally on top of the health care needs of the students in my building because I can only work with what I know. So, that's a frustrating piece for me as far as school nursing is that that piece."

The frustration and concern for safety is enhanced when parents are reluctant to allow the school nurse to contact providers, especially in children with complicated health problems.

> "If you have a complicated health problem, sometimes a parent is not willing to sign a release for you to talk to the physician, because there might be a reason for

> that. They might not want you to know everything that is going on. They want to have more control over what's going on. So, that can be a barrier as far as doing, having a good plan and having up to date current information. So, sometimes that can be a barrier."

Even when the school nurse followed protocol and obtained consent from the parents, the providers or clinic staff might not always honor the request. This can be a barrier as the school nurse is delayed in receiving the information needed to provide care coordination until another consent is signed and returned to the clinic.

> "I have one signed, have the HIPAA consent signed, at the beginning of the year, and he goes to the doctor in December, even though my consent is clear and it says that this is effective for 12 months unless revoked in writing. They didn't accept that so I couldn't get information so each time he was going to go I would have to have another consent signed."

Even when consents are signed and accepted by the provider or staff at the clinic, it might be difficult for the school nurse to reach and talk with the right person. School nurses have to reach out to providers from all across the state as many of their students see specialists in various parts of the state. Once the school nurse successfully reaches the clinic or provider, the telephone game continues with messages being passed among a variety of nurses and doctors within a clinic setting.

> "Some of the details get lost because it goes from the nurse, the triage nurse talks to the doctor's nurse, who talks to doctor, [who] tells his nurse something, who tells [or] either calls the triage nurse and then she calls me back. It's just so many

> steps along the way there and, we know that information every time you transmit it there's a chance of something getting lost or dropped or added [and] that takes time."

School nurses rely on parents to provide much of the information for care coordination. Some parents are not as responsive to the information requests coming from the school nurse, "For parents to get that information to us was somewhat difficult." This school nurse characterized getting information as somewhat difficult but other school nurses provided examples that could more rightly be termed extremely difficult.

> "But I had a terrible time, the most difficult time I had was I couldn't contact the parents on doctor orders I had to give what I needed for a doctor order through the mom and that was really hard because I would have to notify her probably three, four, five, six times and just kept documenting 'notified on such and such, no results, notified on such and such, no results'. I knew what I needed to do to provide good care for her but to get the official doctor's order, yeah, it was difficult."

Another school nurse participant offered:

> "I'll have a parent write that their child has a seizure disorder and I can't reach the parent all year long. Or they have a bee sting allergy but the parent never turns in an Epipen to the health office with a doctor's order for it. Not getting information is the hardest part."

School nurses identified that lack of time was of concern. Accessing information is time consuming. Access to information relies on the parents to consent to release

information or directly provide information. Inability to access information and lack of time were identified as barriers to care coordination by school nurses.

Factors impacting school nurse care coordination for CSHCN.

A total of 19 themes across six study aims have been identified and confirmed with applicable quotations. In order to answer the research question, what factors impact school nurses' ability to perform care coordination activities for children with special healthcare needs?, a final step was taken to distill the 19 themes down to four factors.

The researcher believed the 19 themes could be represented more concisely by defining factors which could encompass the 19 themes into a manageable few. The researcher reviewed the themes looking for logical connections between the themes. A final list of four factors were: school nurses need to establish relationships with a team; information needs to be collected and shared; each child has individualized plans to meet overarching educational goals; and sufficient time is needed.

The 19 themes were related to the four factors in the following way. The factor, school nurses need to establish relationships with a team, encompassed seven of the themes. Those seven themes were: collaboration; parents lead the way; advocacy; liaison to the community; (helping relationships are) essential to success; trust; and support of a team. The factor, information needs to be collected and shared, encompassed seven themes. Those themes were: informal identification process; assessment is foundational; information resources; seeking evidence; individualized communication process; communication; and access to information. The factor, each child has individualized plans to meet overarching educational goals, encompassed four themes. These themes were: overarching goals; individualized planning, individualized care plans; and

templates for plans. The factor, sufficient time is needed, encompassed one theme, that theme was time.

Chapter Summary

In this chapter the results of the survey and semi-structured interviews to describe the study participants and school districts they serve and the thematic analysis for each study aim were presented. The process of deconstructing and reconstructing the data from raw data to factors was described. Two methods for verification of the coding scheme were provided.

This group of school nurses was highly educated and experienced in school nursing. They provided services to a large number of children with a wide variety of medical concerns and family concerns that might impact school nurses ability to provide care coordination. The school nurses provided raw textual data that was analyzed to develop themes and factors to address the study aims and question.

A total of 19 separate themes across the six study aims were identified. The themes identified were: Study Aim 1) collaboration, overarching goals, parents lead the way, informal identification process, advocacy, liaison to the community, assessment is foundational, and individualized planning; Study Aim 2) information resources, seeking evidence; Study Aim 3) individualized care plans, templates for plans, individualized communication process; Study Aim 4) (helping relationships are) essential to success, trust; Study Aim 5) communication, support of a team; Study Aim 6) time, access to information.

From the 19 themes identified there were four overarching factors which could encapsulate all 19 themes. Factors which impact school nurses' provision of care

coordination for CSHCN are: school nurses need to establish relationships with a team; information needs to be collected and shared; each child has individualized plans to meet overarching educational goals; and sufficient time is needed. Figure 3 captures the relationship of the 19 themes to the four factors.

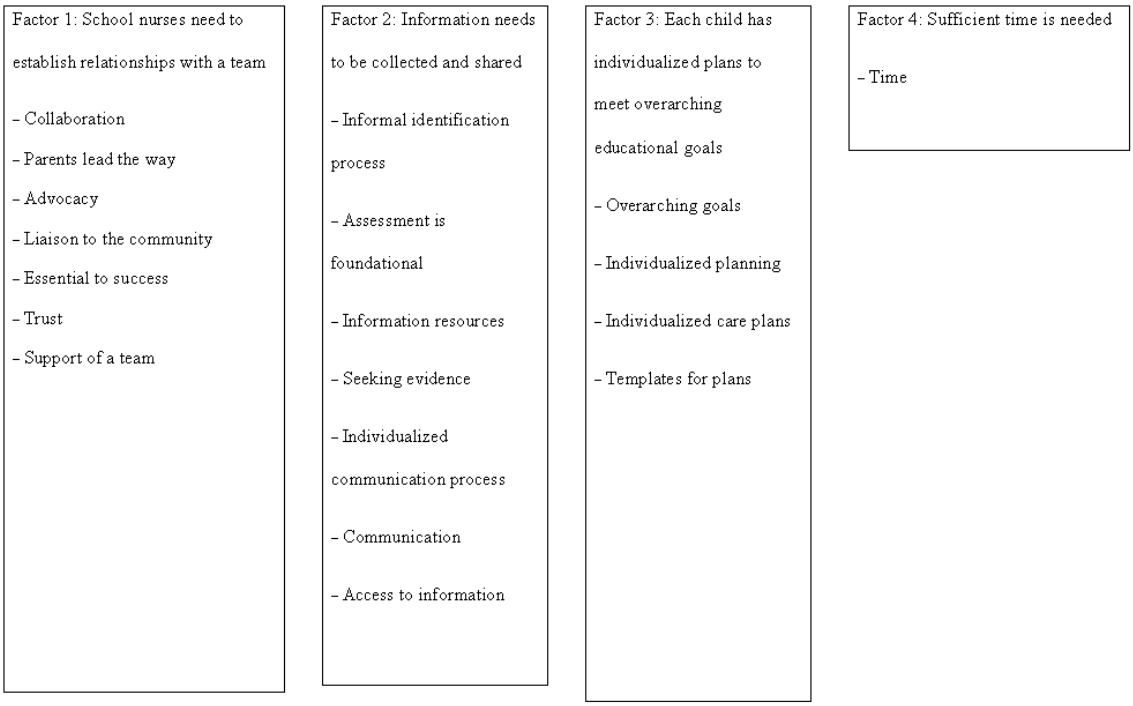

Figure 3: Themes displayed by factor.

Of most concern to the school nurses was lack of time to provide the highest level of care coordination for CSHCN. Time is needed to establish the relationships with parents, staff and healthcare providers. Without these relationships the school nurse is unable to obtain the necessary information needed to develop a plan to meet the educational and safety goals for the CSHCN in school. Time is also needed to communicate the plan out to the team, to oversee and evaluate the effectiveness of the plan and to communicate back any changes needed to the plan. This is an ongoing

process that requires significant time and coordination on the part of the nurse. The implications of the research results will now be discussed.

CHAPTER 5 DISCUSSION

The purpose of this research was to explore the factors which impact school nursing care coordination of children with special healthcare needs (CSHCN). This qualitative descriptive study had six study aims. The analysis of the semi-structured interview data resulted in 19 themes within those six study aims. The 19 themes were then sorted and organized into four factors. These four factors served as the organizing structure for comparing results of this research to the literature. Following comparison of the findings to the literature, this chapter provides recommendations for the future, outlines the strengths and limitations of this research, and summarizes the conclusions of this study.

Comparison to Literature

Four factors impacting school nurse care coordination for CSHCN were identified: 1) school nurses need to establish relationships with a team; 2) information needs to be collected and shared; 3) each child has individualized plans to meet overarching educational goals; 4) and sufficient time is needed for care coordination. In some instances the findings of this study are supported in the literature and in other instances there is disagreement between the findings of this study and previously published findings.

Factor 1: School nurses need to establish relationships with a team.

This factor, school nurses need to establish relationships with a team, encompassed seven themes, including: collaboration; parents lead the way; advocacy; liaison to the community; (helping relationships are) essential to success; trust; and

support of a team. The comparison of the findings of the seven themes of Factor 1 to literature is now presented.

Collaboration.

One theme identified in this study as important to establishing relationships with a team was the collaboration of school nurses with a number of individuals on behalf of the CSHCN when planning and communicating care coordination. Primary care providers were a source of information and provided needed orders and direction for treatments or medications at school. In a study of primary care pediatricians, participants reported they directly contact schools as part of care coordination, however, only 23.3% of the pediatricians reported they always contacted the school, while 60.9% reported they sometimes contacted the school, 15.4% reported they rarely or never contacted the school (Gupta et al., 2004). In comparison to Gupta et al's findings, the school nurses in this current study portrayed the frequency of primary care pediatric contact with the school nurse as a "rare" event.

There is a large discrepancy in frequency of contact perceived by school nurses and the reports from primary care pediatricians surveyed by Gupta et al (2004). This discrepancy might be accounted for because the pediatricians in Gupta et al's study were members of the American Academy of Pediatrics (AAP). As members they might be more actively involved in the efforts to establish medical homes for CSHCN and therefore might be more likely to incorporate the recommendations of the AAP for care coordination in the medical home. ("A medical home is an approach to primary care in which primary care providers, families and patients work in partnership to improve health outcomes and quality of life for individuals with chronic health conditions and

disabilities" (Minnesota Department of Health, 2011b, para. 1).) It might be that the school nurse participants in this study cared for students whose pediatricians were among the 15.4% of those reporting rare contact with the school. One might expect at least one school nurse reporting consistent or even frequent contact from any pediatrician caring for their CSHCN based on the reported frequencies from the primary care pediatricians (Gupta et al., 2004) however this was not the case as the school nurses reported contact from pediatricians was rare.

Parents lead the way.

The school nurses in this study identified the importance of engaging parents in the process of developing plans for care of their CSHCN. Ultimately though the parent makes the decisions related to healthcare plans for their child, consequently the school nurses reported deferring to parents. The parents had the decision making power and were seen in a leadership role in coordinating care. Parents are the ultimate authority in the care of their CSHCN. In a policy statement by the American Academy of Pediatrics (AAP) (2004) on care coordination in the medical home, parents were also identified as the leaders of the care coordination team. The AAP statement includes a caveat regarding parents who are unable to perform the leadership duty. The caveat suggests for those parents unable to lead the care coordination team, the primary care pediatrician assists in designating a person to lead the care coordination team. For CSHCN that person is usually a skilled healthcare professional like a nurse or a social worker (Council on Children with Disabilities, 2005). The school nurses interviewed did not suggest replacing the parent in their leadership role. On the contrary school nurses made efforts to support parents and assist them in any way possible to continue to lead.

The findings of this study and the AAP policy statement were in agreement that parents are in charge of the care coordination efforts. An inconsistency arises when the primary care pediatrician perceives the parent as unable to lead then a substitute is assigned to perform those care coordination duties. School nurses do not report parents as unable or incapable of leading only needing support to continue to lead. The school nurses reported assisting parents to continue in the role of leader for care coordination.

Advocacy.

One role that school nurses played in their relationship with the team was advocacy. School nurses indicated they advocate for students, parents, staff and the school district. The NASN defines the advocacy role of the school nurse as an advocate for provision of quality care for children with chronic conditions (National Association of School Nurses, 2006b). The school nurses in this study described many instances where they fulfilled this role, meeting or exceeding the NASN defined advocacy role.

Two types of advocacy are described in the nursing literature. One type of nursing advocacy is that of political activism and involvement. The other type of nursing advocacy is focused on the patient and access to healthcare. School nurses advocate within the political powers of the school district and legislature for the healthcare needs of students. School nurses also find ways in which to overcome the barriers resulting from disabilities which might impede student educational success (Davis-Alldritt, 2011). The study findings support the dual advocacy roles. School nurses reported working with students to plan for educational success, removing barriers to educational success. The school nurses also reported advocating to school administration, school districts and, public health agencies on behalf of the students and families they work with. This is the

first study to provide school nurse examples of advocacy and confirm that both types of advocacy efforts made on behalf of the students and families.

Liaison to community.

As a member of the team working with CHSN, the participants in this study identified the importance of their role as a liaison to the community. As a liaison to the community, school nurses described engagement or activities with community members such as healthcare providers, public health agencies, families, other school personnel, and policy makers. This theme, being a liaison to the community, is also consistent with one of the NASN key roles of all school nurses identified as "liaison between school personnel, family, community, and healthcare providers" (National Association of School Nurses, 2009, para. 10).

School nurses described instances where they needed to act as a liaison to various members of the community on behalf of their students. The school nurses were able to describe instances of liaison with school staff either in teaching healthcare treatments or needs for CSHCN. This research represents the first research that documents school nurses description of their role as a liaison to the community. Even though the role of a liaison to the community is a key school nursing role defined by NASN, this is the first research to offer real life examples of this role in relationship to care coordination for CSHCN.

(Helping relationships are) essential to success.

This theme, essential to success, is descriptive of the concept helping relationships in the School Nursing: A Framework for Practice (SNFP) model. School

nurses described that taking time to fully develop a helping relationship was essential to successfully planning and communicating care coordination activities. A number of the school nurse participants were unfamiliar with the term helping relationship. When given a definition, the school nurses provided detailed descriptions of the efforts they make to develop a helping relationship and described the essential nature of establishing the helping relationship. Research on the concept of helping relationships in school nursing is lacking. Research on helping relationships in school nursing could assist school nurses in a deeper understanding of their practice framework.

Trust.

Trust was another concept related to helping relationships in the SNFP. School nurses identified the importance of trust which is required for a helping relationship to be formed. There is no research on the importance of trust in school nursing care coordination. There is however research on the engenderment of trust between school nurses and students. Summach (2011) interviewed six school nurses seeking to identify what behaviors or interactions on the part of the school nurse engendered trust in high school students. Subjects in the Summach's (2011) study identified both nurse based and school based factors which impact the establishment of a trust relationship. The nurse based factors were: nurse characteristics, interaction characteristics and communication techniques. The setting based factors included setting characteristics, student characteristics and role responsibilities (Summach, 2011). Summach's research differs from this study because Summach's study sought to describe the development of trust and did not to establish the importance of trust in a helping relationship as described by the school nurses in this current study.

The nature of trust between families of children with disabilities and school personnel was the subject of a qualitative study by Angell, Stoner and Sheldon (2009). The researchers acknowledge the importance of establishing trust but wished to more fully understand trust and how it is established between families of children with disabilities and school personnel, particularly teachers. Three factors were identified: family, teacher and school. Within those three factors nine themes arose. Those themes were grouped within the three factors. Family factor themes were: disposition to trust, communication from the child, and history of trust. Teacher factor themes were: authentic caring, communication and knowledge. School factor themes were; school climate, teaming and school services (Angell, Stoner, & Shelden, 2009). School nurse participants in this study described similar factors which might impact trust in particular history of trust, disposition to trust, authentic caring, communication, knowledge and teaming. The school nurses did not describe communication from the child, school climate or school services as factors impacting trust.

The research by Summach (2011) addresses the factors engendering trust development between school nurses and high school students. The research by Angell, Stoner and Sheldon (2009) addresses the factors which impact trust development between families of children with disabilities and school personnel. Both studies are founded on the premise that trust is important and discovering what facilitates trust will enhance the school nurse or school personnel's ability to promote trust. The premise of the importance of trust is consistent with the findings from this study.

Support of a team.

School nurses reported they needed to develop support of a team including parents and school personnel in order to effectively plan and provide care coordination services for CSHCN. This is similar to the findings by Maughan and Adams (2011) who investigated educators' and parents' perceptions of what school nurses do. Maughan et al found that both parents and educators identified two factors impacting their perception of the school nurse: professionalism and being a team player. The school nurses professional interactions with educators and parents influenced the opinions of educators and parents; the more professional the interaction the more positive the perception of the work of the school nurse. The quality of interaction and not the quantity of interactions was important to parents and educators when placing a value on the work of the school nurse. In addition to the professional interactions, educators and parents valued and understood that school nurses needed to be proactive in providing information and needed to act as part of the education team. As part of the educational team, the school nurse needs to understand the organizational culture of each school in order to become a successful member of the team (Maughan & Adams, 2011). The nurse needs not only the support of the team but needs to be a well respected member of the team, a team whose focus is educational success. More research is needed in this area to discover how other members of the educational team perceive the role of the school nurse as a member of the educational team.

Factor 2: Information needs to be collected and shared.

The factor, information needs to be collected and shared, encompassed seven themes. Those themes were: informal identification process; assessment is foundational; information resources; seeking evidence; individualized communication process; communication; and access to information. School nurses developed a variety of means to collect and share the information needed to provide for the healthcare needs of CSHCN in school. Comparison of the seven themes of Factor 2 to the literature follows.

Informal identification process.

School nurses acknowledged that there is not a standard process for identifying CSHCN in their school who might benefit from school nursing care coordination. School nursing literature to support or refute this result is lacking. The process of identification of CSHCN for care coordination might be a function of the school culture and system. Therefore a standard process might not be feasible. Without further research on this theme, school nurses will continue to wonder whether the approach to identification they take within their schools is the most effective approach.

Assessment is foundational.

The nursing process is foundational for providing care; the first step of this process is assessment. Assessment includes both the collection of data and the interpretation of the data (Wold, 1981). Data collection might include a health history, an interview, a physical examination, and a review of health records. The interpretation of the data results in documentation of identified problems (Christensen, 1981). Participants

in this study described the need to perform an assessment as a prelude to development of care coordination plans for CSHCN.

Assessment was not one of the activities described by the AAP policy statement on care coordination for CSHCN in a medical home. Primary care pediatricians receive plans from specialists and perform assessments as part of primary care management (Council on Children with Disabilities, 2005). The activities related to care coordination rely on a plan being present and the primary care pediatrician is responsible for assuring the plans are carried out.

In the Factor 1 comparison to literature a discrepancy between primary care pediatrician reported communication and the school nurse participants' characterization of communication from a primary care pediatrician as a rare event. Therefore the school nurse must perform the assessment prior to planning. Research on how school nurses conduct assessments for CSHCN is lacking. Research could provide direction to the school nurse on the type of data needed, the process for gathering data and the interpretation of data gathered for developing care coordination plans for CSHCN.

Information resources.

Part of the assessment process is collecting data or information. The school nurses sought information from multiple sources, parents, healthcare providers, students, health records, educational records, books, and the internet. In studies conducted by Adams and McCarthy (2007) and Adams (2009), school nurses reported similar information sources as those cited by the school nurses in this study. Information sources cited by the nurses in Adams's study were peers, internet, books, and other healthcare professionals (Adams & McCarthy, 2007; Adams, 2009). School nurse participants

reported seeking out the same resources but added additional resources such as the Minnesota Department of Health and the local public health department.

The internet was one resource frequently cited by school nurses in this study when seeking information in planning care coordination for CSHCN. The school nurses searched credible websites such as Mayo Clinic, WebMD, NIH.gov and State of Minnesota Department of Health. These websites provide information which is general, well supported and current. Surprisingly, school nurses did not mention using disease specific websites as a source of information for rare or complex medical conditions found among their CSHCN. For example, one nurse described a student with myotonic muscular dystrophy (MMD). The Muscular Dystrophy Association provides a detailed overview of MMD (Muscular Dystrophy Association, 2009) which could be useful to develop an IHP for a child with MMD, yet none of the 27 school nurses interviewed mentioned disease specific websites for rare conditions as a resource. A site maintained by a disease specific organization was cited as a criterion for judging credible internet sites (McHugh, 2002). School nurses did not provide evidence for use of this type of credible internet site for information needed when planning care coordination activities for CSHCN.

Seeking evidence.

While credible resources of information were identified by the school nurses, they also identified that evidence for school nursing practice is sometimes lacking. Evidence based practice (EBP) involves the combination of evidence from multiple sources to develop guidelines for optimal patient care. EBP is not unique to the nursing profession; physicians, therapists, and pharmacists all look to the literature for evidence of best

practice. NASN supports the development of EBP yet implementation of guidelines is slow to transfer from research to practice, on average 20 years (Adams & McCarthy, 2005). There is a systematic process for developing EBP guidelines which is a scientific process subject to review by experts.

The steps in this systematic process required for to developing EBP guidelines are: identify a problem, perform a systematic review of the professional literature, evaluate the evidence, make recommendations for practice, present the guideline in a standardized format and submit the guideline for internal and external review (Adams & McCarthy, 2005). School nurses have begun to develop EBP for problems related to school nursing concerns.

Problems which have been identified and addressed by school nursing EBP guidelines are pediculosis, activity, latex allergies, asthma management, and wound and laceration treatment. Once the guideline is developed it is subject to peer review and comment. When the guideline is finalized, then it must be disseminated to the front line school nurse. In order to assist in the development and dissemination of EBP guidelines for school nursing, the University of Iowa is planning a center for EBP guidelines for school nursing (Adams & McCarthy, 2007). The function and purpose of the center will need to become a familiar resource for school nurses so they can access and keep current with school nursing research.

In an effort to determine factors associated with the use of EBP guidelines in school nursing, Adams (2009) surveyed 242 school nurses during a national conference. Familiarity with and adherence to EBP guidelines varied widely. Subjects reported 82% allowed students to carry inhalers for asthma control but only 4% of the subjects allowed

students to return to class after head lice were discovered even though isolation is no longer recommended (Adams, 2009). Inhibitors to these practice change were identified. Key inhibitors were lack of support for implementing the change and lack of skill in evaluating recommended changes.

Even though there are some EBP guidelines developed, these guidelines do not address some of the more complex needs of students with chronic health conditions who might benefit from care coordination. The EBP guidelines currently in place address common school nurse problems. As the process for EBP guideline development matures there will be more opportunity to address more complex conditions found in CSHCN and managed by school nurses.

Individualized communication process.

School nurses reported that they individualized their communication to the educational team, families and other healthcare providers. School nurses individualized the communication based on the needs of the receiver. An example of individualized communication was the majority of the school nurses reported they wrote plans in simple terms or translated the IHP nursing language before sharing the individualized plan with the teacher or paraprofessional in the school. It is appropriate for an IHP to be written so that the receiver comprehends the information within the plan. Findings in this study demonstrated that school nurses refrained from writing plans using nursing terminologies recommended by NASN and only used local terms understandable by their audience.

While care should be individualized, the NASN supports the use of a standardized nursing language in school nursing practice. In a NASN position statement this support is described as follows, “NASN believes school nurses should use the opportunity to

contribute to the implementation, evaluation, and development of nursing languages relevant to school nursing. Finally, NASN supports the use of standardized nursing languages in school nursing practice, in electronic health records, and school nursing education programs" (National Association of School Nurses, 2006c, para. 1). In particular the NASN supports the use of North American Nursing Diagnosis Association (NANDA), Nursing Interventions Classification (NIC) and Nursing Outcomes Classification (NOC). The position of the NASN suggests NANDA, NIC and NOC are the preferred language because "represent the nursing process, are supported by research, and facilitate continuity of care across settings" (National Association of School Nurses, 2006c, para. 9). The school nurses interviewed did not report consistent or even frequent use of a standardized language in the development of IHPs. The most common reason given by the school nurses for not utilizing NANDA, NIC and NOC was the need to communicate to non-nursing personnel the needs of the student. In order to communicate clearly, the majority of the participating school nurses reported they wrote plans in simple terms or translated the IHP nursing language before sharing the plan with the teacher or paraprofessional in the school.

Two concerns arise from this identified discrepancy. First, the school nurses are spending time producing two documents addressing the same content; one care plan in a standardized language for use by the school nurse and one in simple terms for teachers and paraprofessionals. School nurses already identified time as an inhibitor to care coordination so every effort should be made to reduce unnecessary paperwork. Secondly, without the use of a standardized language the ability to clearly articulate, research, and communicate the work of school nurses across settings is limited. The need to use local

easily understood terms for the team collaborating to care for the CHSN and also have standardized terms to compare across settings can be improved in the future with documentation in an electronic system.

The use of local terms for users mapped to standardized terminologies for the profession have been done in other settings. Lee and Park (2010) demonstrated that they could successfully map over 62% of nursing statements written in local language to the International Classification for Nursing Practice (ICNP). The statements were taken from documentation of telephone consultations with nurses and patients who had undergone recent ophthalmologic surgery (Lee & Park, 2010). A similar study could be performed on school nurse generated IHPs to determine whether the nursing statements within and IHP could be mapped to NANDA, NIC and NOC. Standardization of language would be a first step in researching the content, consistency and outcomes of IHPs developed as part of care coordination for CSHCN. Research on student outcomes as a result of care coordination activities outlined in an IHP would be possible if a standardized nursing language was used.

Based on use of a standardized terminology, the Omaha System, outcomes in public health nursing were researched by Monsen, et al (2010). Findings from this research indicated a perceived improvement in client outcomes as a result of public health nursing care. The findings from Monsen, et al were possible because the Omaha System nursing language was used to document problems and outcomes. A reported 84% improvement of documented nursing problems substantiates the importance of public health nursing visits (Monsen et al., 2010). This finding is quantifiable because of the presence of the standardized nursing language. School nursing could model this type

of research by the consistent use of NANDA, NIC and NOC in school nursing care plans for CSHCN.

Some school nurse participants did report utilizing standardized plans from professional organizations like the Food Allergy and Anaphylaxis Network and the Epilepsy Foundation. These plans are freely available on the internet as a resource to school nurses. These plans could be formatted such that a standardized nursing language is imbedded into the plan for outcomes comparison. Providing translations from local terms to standardized terminology could assist school nurses in establishing measurable outcomes resulting from school nurse care coordination for CSHCN.

Communication.

The theme communication was identified as a facilitator for care coordination. Communication has been a recurrent theme in this discussion. Communication between primary care pediatricians and the individualization of communication between the school nurse and non-nursing school personnel have already been addressed. Communication between school nurses and families will now be addressed.

The school nurses emphasized the importance of listening to parents and for the parents to feel they have been listened to. MacKean, Thurston and Scott (2005) interviewed parents of children with developmental disabilities. Parents were able to describe healthcare providers as exhibiting two types of competency, technically competent and relationally competent. Relational competencies described were interacting with children, caring and communicating with parents. Those healthcare providers identified as exhibiting good communications skills were honest, open and direct in their manner, sought out and listened to opinions of the parents and valued the

input provided by parents in planning for the needs of their child (MacKean, Thurston, & Scott, 2005). Similar findings were discovered when parents of preterm infants in ICU were interviewed regarding effective and ineffective communication between nurses and parents. It was found that those nurses who had effective communication provided to parents not only information but also communicated in a reassuring and respectful manner (Jones, Woodhouse, & Rowe, 2007). The school nurses in this study reported communication with parents needed to be respectful of the rights of the parents as decision makers and leaders of the care coordination team.

Access to information.

The school nurse participants identified that the lack of access to information was an inhibitor of care coordination for CSHCN. All the school nurses reported having information sources such as books, internet, school personnel and other health professionals. Obtaining information especially medical records from physicians was difficult for school nurses. A common reason mentioned by school nurses for lack of success in obtaining records was the lack of the appropriate release from parents to obtain the information required for planning care coordination for CSHCN.

Another instance where lack of information becomes a concern is the treatment of CSHCN in an emergency situation. This concern prompted the American College of Emergency Physicians to issue a policy statement. This policy statement on an emergency information form for CSHCN supports four propositions. These propositions are 1) a mechanism for the quick identification of a CSHCN, 2) information on the medical needs of the CSHCN should be in an accessible format, 3) the format for storage of information might vary based on the needs of the provider and patient and 4) a

universally acceptable form should be distributed for use by physicians, parents and other care providers (American College of Emergency Physicians, 2010). This universal form is one solution to information access that might assist school nurses. With the increasing development of personal health records (PHR), a PHR for CSHCN might offer another gateway to information for school nurses when planning care coordination.

Information contained in student health records "in either paper or electronic form must be confidential, secure, accessible only by authorized staff, and protected from loss or destruction" (National Association of School Nurses, 2004, para. 6). Some school nurses expressed concern about distribution of care plans containing health information to other individuals in the school setting. The school nurses were concerned that information on a paper form could be inadvertently exposed for another student or staff member to read. Information could be shared electronically through e-mail or alerts within an electronic student record system. This method while not fool-proof seemed to the nurses as more secure.

School health records in most instances are secured in accordance with the Family Education Right to Privacy Act (FERPA) requirements (Bergren, 2001). FERPA has requirements similar to the Health Insurance Portability and Accountability Act (HIPAA) (Bergren, 2001). Schools and school districts are responsible to ensure the security and confidentiality of educational records. Individual access to educational records is based on a need-to-know which in some school districts is still to be defined. Electronic school records development has reflected the requirements for security and confidentiality with the ability to audit who has accessed a record and assigning levels of security to portions of the entire school record (Bergren, 2001). This level of security is in alignment with the

requirements of electronic health records in the ambulatory and acute care settings making the secure transfer of data between school health office and clinic or hospital a possibility.

Electronic school record development has been similar to electronic health records where two options exist for product selection. One selection might be best of breed where individual modules for each function are selected and interfaces within these modules are created at the organizational level or an integrated enterprise system where interfaces already exist within the software (Thede & Sewell, 2010). Electronic school records have the distinct advantage over paper records in the ability for one to enter data within one module and automatically reuse of that same data in other modules. For school nurses this would allow for the entry of health information into the student record and that same information could appear in healthcare plans or special education documentation without the school nurse re-entering the data in both places. Information about student demographics, which for example might be controlled through the business office, could populate the care plan templates used by school nurses and stored within the health office module of electronic school record. This model of data sharing should be encouraged in the future design and development of electronic school records.

Factor 3: Each child has individualized plans to meet overarching educational goals.

The Factor, each child has individualized plans to meet overarching educational goals, encompassed four themes. These themes were: overarching goals; individualized planning, individualized care plans; and templates for plans. A comparison of the literature for these four themes is now presented.

Overarching goals.

The two goals identified by the school nurses were good education and safety. These goals are consistent with goals contained in the NASN issue brief on school nursing management of children with chronic health conditions. The NASN issue brief states "The goal of school nursing services is to enable students to access academic programs in the least restrictive environment through safe and appropriate management of health conditions and to support student academic success." (National Association of School Nurses, 2006b, para. 5). Findings from one study confirmed that CSHCN are more likely to have educational struggles (Forrest, Bevans, Riley, Crespo, & Louis, 2011). Those CSHCN identified in the study with functional limitations or emotional behavior disturbances were significantly more likely to have lower grades, lower scores on standardized tests and to have lower parent reported academic achievement (Forrest et al., 2011). The recommendations arising from the study suggest early identification and collaboration between the educational system and healthcare providers to ensure that CSHCN have the opportunity for educational achievement and develop their full potential in learning (Forrest et al., 2011). Management of health conditions which limit academic achievement is the focus of school nursing. To determine effectiveness of school nursing care coordination, measurement of student academic achievement would be an outcome measure worthy of investigation.

Individualized planning.

The theme individualized planning represents the descriptions by the school nurses of the efforts they make during the planning phase to identify the individual needs

of the CSHCN to meet their educational and safety goals. Additionally, school nurses described how they individualized planning based on the school personnel who might be required to manage plans established. Previously a discussion of the school nurses efforts to develop plans which were understandable to non-nursing school personnel was described. The school nurses' individualized planning on behalf of CSHCN recognized the uniqueness of each child and their life situation.

Mäenpää and Åstedt-Kurki (2008) described how school nurses and parents cooperate in promoting the health of students in elementary and secondary school. Elements of this parent-school nurse cooperation included evaluation of the student's life, and family health situation along with assisting students with difficulties. School nurses described basing plans for assisting students on the individual circumstances of the child (Mäenpää & Åstedt-Kurki, 2008). The results from the interviews with school nurses in Mäenpää and Åstedt-Kurki (2008) are consistent with the reports from school nurses in this study. School nurses acknowledged that children with the same medical concern still require individualized planning because of their unique life situation or impact on their health. Therefore, the findings of this research are consistent with the literature.

Individualized care plans.

Previous research found that 23.8% of school nurses surveyed had written IHPs or ECPs for CSHCN. In this same study only 26.5% of the respondents felt the IHP or ECP was of value in caring for CSHCN (Heller & Tumlin, 2004). In this study the school nurses interviewed all responded that they developed either IHPs or ECPs for students. There is a discrepancy in the rates of IHP development cited by Heller & Tumlin (2004) (23.8%) and that found in this research (100%). The school nurses articulated that these

plans needed to be written in such a way that was understandable to the teachers or paraprofessionals who were responsible for monitoring or providing care for CSHCN. The question was not asked as to the perceived value of the IHPs to the teachers or paraprofessionals but clearly these nurses made efforts by adjusting the language utilized in the plans to make sure the plans were clear and understandable. As previously noted one method to assist in clarifying IHPs for the end user was to remove standardized nursing language from the plans.

Templates for plans.

Earlier in the discussion of Factor 1 on the theme individualized communication process it was noted that some of the school nurses described using template plans from the Food Allergy and Anaphylaxis Network (FAAN). Other school nurses reported modifying this plan to meet the needs of their schools or districts. This type of plan is an emergency care plan which is prepared by school nurses for medical concerns which could be life threatening such as allergies, asthma and diabetes (National Association of School Nurses, 2006b). The format of these plans is not prescribed by the NASN for school nurse. Choosing a care plan template should include evaluation of the information contained within the plan and the readability or understandability of the plan for non-nursing personnel who might be required to provide care based on the contents of the plan.

Powers, Bergren and Finnegan (2007) compared food allergy emergency care plans from 60 school nurses to the FAAN plan. Ninety-eight percent of school nurses reported they care for children with food allergies in their schools. Of the school nurses who provided plans for comparison, 15% of the plans were the current FAAN plan, 35%

were a previous version of the FAAN plan and the remaining 50% were not based on the FAAN plan. The current FAAN plan has 32 criteria to be completed. When compared to these 32 criteria it was found that among the 60 plans evaluated the criteria were met between 15% and 90% of the time. The most common criterion met was the instruction to call 911 for an emergency. The criterion least met was detailed instructions for the use of Twinject epinephrine for emergency rescue medication (Powers, Bergren, & Finnegan, 2007). Powers, Bergren & Finnegan (2007) suggest "It is unnecessary and risky for school nurses to develop their own plans or to alter the FAAN plan." (Powers et al., 2007, p. 255). They acknowledged that school nurses at the point of care have neither the time nor the expertise to create this type of research based, best practice plans (Powers et al., 2007). The school nurse participants interviewed on care coordination for CSHCN understood the need to use template care plans, identified time as a factor that impacts a school nurse's ability to perform care coordination and desired evidence based guidelines for practice. These findings are consistent with the findings from Powers, Bergren and Finnegan (2007).

Factor 4: Sufficient time is needed.

There is only one theme associated with factor four. This theme is time, which was identified as an inhibitor of school nursing care coordination for CSHCN.

Time.

One factor identified by school nurses which impacts their ability to provide care coordination for CSHCN was time. Lack of time was also cited as an inhibiting factor when primary care pediatricians were questioned on their provision of care coordination

services in pediatric medical homes (Gupta, O'Connor, & Quezada-Gomez, 2004). One reason for lack of time articulated by the school nurses in this study was the large number of students for which they were responsible.

The National Association of School Nurses (NASN) recommends a minimum of one school nurses for every 750 students in the general school population. This recommendation was first identified in 1972 as the NASN Caseload Position Statement (Garcia, 2009) which has been updated and revised in the last 40 years but the ratio has not changed (National Association of School Nurses, 2010). For school nurses with student populations that might require daily school nursing services or interventions, the recommended ratio decreases to 1:225 and the ration decreases to 1:125 when the students population includes children with complex medical needs (National Association of School Nurses, 2006). These ratios are recommended by the NASN but do not arise from research. These ratios are generally accepted in the school nursing community and have been supported by the Department of Health and Human Services (DHHS). The ratio of 1 nurse for 750 students is included as a recommendation in the DHHS Health People 2020 initiative as Education and Community Based Program Recommendation 5: "Increase the proportion of the Nation's elementary, middle and senior high schools that have a full-time registered nurse-to-student ratio of at least 1:750" (US Department of Health and Human Services, 2011, p. 9).

All the school nurses in this study indicated they provide services or interventions for CSHCN. The nurse to student ratio should then be in the range of 1:225 to 1:750. In this study there were only four school nurses (14.8%) reporting less than 750 students under their care. These findings are consistent with the report from the NASN comparing

each state on their nurse-to-student ratios. Minnesota was 38th out of 50 states with an average nurse-to-student ratio of 1:1773 (National Association of School Nurses, 2011). Four of the school nurses (14.8%) reported covering only one school building. Travel time from building to building will ultimately consume time in each school nurse's day just to meet the requirements of CSHCN in each building. Time impacts both primary care providers and school nurses in their efforts to provide care coordination for CSHCN.

Consistencies and inconsistencies between this study's findings and literature or standards have been presented. Arising from the comparisons are recommendations. The recommendations for school nursing practice, education, policy and research are now presented.

Recommendations

A number of recommendations arose from the analysis and reporting of the results of this qualitative descriptive study. The recommendations from this study are categorized based on their impact on practice, education, policy and research and based on a synthesis of all four factors and all themes within each factor. Following the recommendation statement the reader will see the theme related to the recommendation in parenthesis. This is done to assist the reader in linking the recommendation to the comparison of the literature by theme.

Practice.

School nurses should not be responsible for more than 750 students. (time)

The NASN established a ratio of 1:750 for a school nurse who only cares for students in the general population, yet only four nurses in this study actually had a ratio

of nurse to students that was less than this ratio. Exceeding this recommendation raises serious concern about school nurse's ability to provide high quality care to students. The school nurses in this study were able to manage many more than 750 but expressed concerns for the quality of care provided.

School nurses should develop a consistent approach to identification of students who might benefit from school nurse care coordination efforts. (informal identification process)

Much inconsistency was noted in the methods employed to identify students who might benefit from care coordination. Various methods such as parent questionnaires, parent report, teacher report, team meetings and happenstance were identified. The most concerning situation to this researcher was the identification of a student with a chronic medical condition as a result of a crisis which arises during the school day. The school nurse might be faced with an emergency that had it been known could be managed safely and cared for in the school. Because of the unknown component a call to 911 or a trip to clinic might be the only option. It is recommended that school nurses within their school districts clearly identify and initiate approaches to be taken to identify CSHCN who might benefit from care coordination.

Consistent utilization of standardized nursing language in IHPs and the development of a translation of the nursing language into local terms. (individualized communication process)

The NASN supports NANDA, NIC and NOC as the preferred languages. The adoption of a standardized nursing language will support school nursing research to link

outcomes to school nursing interventions. The concern of the school nurse participants still remains regarding translation of nursing language to local terms for teachers and paraprofessionals. A partnership between NASN and terminologists could increase the value of both having a user friendly document and capturing standardized data for reuse in research.

Increase school nurses awareness of the available care plan templates. (templates for plans)

Findings suggest that only 50% of school nurses used a FAAN emergency care plan template for children with food allergies. This plan is an evidence-based, best practice plan which contains 32 criteria for completion of the plan. School nurses might be unaware of the plan. It is recommended that the NASN review care plan templates and recommend the use of credible plans to their membership. An electronic link to the plan should be imbedded in the NASN website for the convenience of the school nurses seeking to use the plan.

Education.

Recommendations for increased education of school nurses arose from the research findings.

School nurses should have a clearer understanding of the SNFP, especially the concept of helping relationships. (helping relationship are essential to success)

The SNFP is widely accepted in the school nursing community yet one of the components seemed unfamiliar to many of the school nurse participants. During the interview process, many of the school nurses did not initially understand the term,

helping relationships. A definition was provided to the school nurses and then their responses were obtained. The school nurses easily described the importance of helping relationships and examples of with whom and how they establish a helping relationship. It is recommended that the model of SNFP become more integrated into school nursing practice with particular focus on the concept of helping relationships.

Education on the framework could be incorporated into training sessions by state affiliates of NASN as part of the new school nurse training offered at the beginning of the school year. This framework should be available for review on NASN website for review by all school nurses. NASN might offer presentations or posters at the annual conference for researcher using the framework as part of a study. These approaches would reach new school nurses, conference attendees at school nursing conferences and individual nurses seeking information on the SNFP from the NASN website.

Educate school nurses on use and development of evidence based practice guidelines. (seeking evidence)

The school nurses described a desire to have more evidence for their school nursing practice. The availability of EBP guidelines and the availability of the University of Iowa center to support EBP guideline development for school nursing needs to be disseminated to the front line school nurses. These resources might prove invaluable to school nurses yet the school nurses interviewed did not indicate they were aware of these resources when planning or communicating care coordination needs for CSHCN. Strategies for dissemination of information on EBP guideline development to school nurses might include: release of an announcement of new EBP guidelines to the school nurse list-serve with a hyperlink to the actual guideline; advertisement in the professional

journal of NASN, *The Journal of School Nursing*, when a new EBP guideline is published: and creating a list-serve from the center to support EBP guidelines for interested school nurses to join which provide an alert when new EBP guidelines are available.

Policy.

Two recommendations for changes to policies are made. These two changes would assist the school nurses obtaining access to information necessary for planning and communicating care coordination activities. Access to information was considered an inhibitor by the school nurses to successful planning for the care coordination needs of CSHCN. Ultimately the goal of the policy changes would be to improve the quality of care provided by improving access to information needed for planning care.

Primary care providers for CSHCN should provide an option for parents to sign an annual release of information statement including school nurses. (collaboration)

Some of the burden of identification of CSHCN and notification of the school nurse needs to lie with the primary care provider for CSHCN. The primary care provider is responsible to coordinate the care between all healthcare providers including specialists. Unfortunately school nurses are often left out of the communication loop and receive little or no advance warning of a student who might need healthcare services in school. One approach to remedy this situation would be to encourage primary care providers of all children to include an option to release information to the school as part of the standard annual privacy statements commonly signed. It would be appropriate to have the dates of the annual renewal correspond with the school year so the school nurses

would be able to consult with the provider throughout the entire school year, not just January to January. This recommendation might be accomplished by engaging the state departments of health who certify health care homes (medical homes). The providers in health care homes work with patients and families to improve outcomes though care coordination and cooperative management for individuals with chronic illnesses. The state could recommend this change in policy to providers who apply as a health care home.

Accelerate the development of personal health records for CSHCN. (access to information)

School nurses described the difficulties they faced when trying to access medical records for CSHCN. Some of the delay was a result of reluctance on the part of parents to sign a release. Some of the nurses suspected it was a desire to control the amount of information the school nurse had access to. Personal health records (PHR) controlled by the parents would be a viable solution to the concern raised by school nurses, lack of access to information. The importance of development of PHRs for healthcare consumers is reflected in the current healthcare reform policies. The Office of the National Coordinator launched an effort for all consumers to be engaged in use of health information technology to manage their own health. One means of consumer engagement is through the development of personal health records (Department of Health and Human Services, 2006). This recommendation is consistent with national efforts.

PHRs maintained by families of CSHCN might contain data to augment the assessment data collected by the school nurse as part of the planning for care coordination for CSHCN. This researcher recommends the development of a CSHCN

focused PHR. Specialized components of the PHR would contain opportunities for data entry of information specific to the needs of CSHCN. Additionally the PHR should be designed so that parents would have the ability to release as much or as little information as they saw fit and to whomever they assign rights of access to the PHR.

Increase adoption of integrated electronic school records. (access to information)

School nurses should work closely with school district administration to select and adopt an integrated electronic school record which contains a school health record. School nurses should be involved in the selection of the electronic record to ensure that data sharing within the record meets the needs of the school nurse. School nurses will need to ensure that any electronic record system selected and adopted meets the security and confidentiality requirements of FERPA. Ultimately the goal of an electronic school health record would be the ability to exchange data with electronic medical records held by clinics and hospitals. Design and development of electronic school health records would need to attend closely to the goal of data exchange between all healthcare providers caring for CSHCN.

Research.

This research was designed as a qualitative descriptive study and foundational for future research. As the themes within factors were compared to literature, a number of future research possibilities arose. Questions are presented with the theme to which they relate in parentheses.

Questions arising from this study for future research initiatives include:

1) How do school nurses develop trust with parents of CSHCN? (trust)

2) How do students with current, complete IHPs compare on educational outcomes to those CSHCN without current, complete IHPs? (overarching goals)

3) How does the variation in assessments influence care planning and outcomes for CSHCN? (assessment is foundational)

4) What criteria do school nurses include in IHPs for CSHCN? (individualized care plans)

5) How are school nurses perceived as members of the educational team by school personnel? (support of a team)

6) How do school nurses advocate of families and children with special healthcare needs? (advocacy)

7) How much time do school nurses devote to care coordination for CSHCN? (time)

8) What is the appropriate staffing ratio of school nurse to student based on the acuity of CSHCN? (time)

Although not exhaustive, the above list represents some potential next steps in research arising from this study.

Strengths and Limitations

There were both strengths and limitations to the current study. In qualitative research some of the strengths include the ability to obtain an in depth understanding of a phenomenon from relatively few individuals, the data collected is rich in detail of the phenomenon being studied, interviews can be modified in real time to gain a better understanding of the subject at hand, data related to the human condition or experience

can be very compelling, subtleties and complexities of a topic are discovered which might be missed utilizing other approaches, the data collected are usually in the participant's naturalistic setting, and analysis might describe both the individual responses and cross case comparisons (Anderson, 2010).

Limitations to qualitative research include: generalizability of knowledge gained to other people or settings; it is difficult to make quantitative predictions from qualitative data; analysis and data collection are time consuming; and the results are more susceptible to the influence of the researcher's biases or beliefs (Anderson, 2010). Individually the strengths and limitations of this research are addressed.

Strengths.

One of the strengths of this study was a sufficient sampling of school nurses for interviews to obtain rich descriptions about school nurse care coordination for CSHCN. While 27 participants represent approximately 2.5% of all possible school nurses in the State of Minnesota, when interviewing the last participants, comments shared affirmed previous participants' descriptions and new ideas were not emerging, saturation was achieved. According to Sandelowski (1995), this sample size is appropriate for qualitative descriptive research. Interviews with the 27 school nurse participants lasted 30 to 45 minutes. The length of the interviews was sufficient to provide rich details regarding the phenomenon. Nineteen themes arose from the data which supports the statement of the richness of the detail provided by the interviewees.

The use of a semi-structured interview tool allowed the researcher to modify the interview questions in real time to capture additional aspects of the phenomenon. Some of these aspects were either subtle or complex in nature. Additional questioning resulted

in a fuller understanding of these aspects. For example, the interview guide included questions on the type of healthcare plans developed. As the interviews proceeded an additional question on standardized nursing languages was added to gain insight into the communication process the school nurse uses with school staff. This modification to the interview guide led to a deeper understanding of the format which school nurses use to develop care plans.

School nurse were interviewed about a familiar process in a naturalistic setting. They were interviewed during the school year and in the majority of instances the interviews were conducted in the school health office in person or over the phone. During the interview notes were taken and provided an opportunity for the researcher to develop cross interview comparisons when repeated concepts or key words appeared during interviews. These field notes provided the foundation for the coding scheme developed for the analysis.

As a result of the analysis a compelling picture of the factors which impact school nurse care coordination for CSHCN was presented. Overall this research represents a strong qualitative descriptive study. Although this researcher made every effort to strengthen this study, certain inherent limitations to qualitative research must be addressed.

Limitations.

The greatest limitation to any qualitative research is generalizability of the findings. As previously described qualitative research uses the term of transferability and not generalizability. Rich descriptions are provided for readers to determine whether results and conclusions of this study have meaning to their situation or their context. In

quantitative research predictions might arise from significant findings. These predictions often help in determining whether the results are applicable or meaningful to other populations. Quantitative predictions were not developed from the qualitative data collected in this study. Therefore the reader must determine individually whether the results are transferable to their circumstance.

Another limitation is the time consuming nature of qualitative data collection. The data collection for this study was accomplished over a relatively short period of time, less than two months. The short time span supported the consistency of the data collection which supports trustworthiness of the research.

Personal beliefs and experiences can influence the results of a study. The researcher made every effort to confirm with other qualitative researchers the process and logic of the coding scheme. Journaling was used during the study to capture the researcher's impressions and potential bias in interpreting findings. Every effort was made to present a rigorous and unbiased representation of the data collected to answer the research question; what factors impact school nurse care coordination activities for CSHCN?

Conclusion

The purpose of this study was to explore the factors which impact school nursing care coordination of CSHCN. The purpose was addressed by interviewing 27 school nurses. Analysis of the textual data resulted in identification of four factors which impact school nurses' provision of care coordination for CSHCN: school nurses need to establish relationships with a team; information needs to be collected and shared; each child has individualized plans to meet overarching educational goals; and sufficient time is needed

for care coordination. Within these four factors 19 themes arose from the analysis of the textual data. These themes address specific aspects of the four identified factors. In the discussion section a comparison to literature was presented, recommendations for enhancement of school nursing practice, education, policy and research were made and strengths and limitations of the research were identified.

This study expands knowledge about the factors which impact school nursing care coordination of CSHCN. The school nurse participants in this study provided insights into the care coordination efforts they make on behalf of the CSHCN in their schools. The school nurses provided care for a large number of students, well beyond the recommended levels. They collaborated with a number of individuals to assess the needs of CSHCN, to develop plans to meet identified needs and to communicate the needs to individuals responsible for implementing the plans. These care coordination activities of the school nurses occurred within the confines of an educational system with a focus on the educational goals established for CSHCN. The school nurses developed plans to mitigate the impact of health concerns on educational success for CSHCN. Time and access to information were the factors that most negatively impacted school nurses when attempting to provide care coordination for CSHCN.

The school nurses provided service between the educational and healthcare systems beyond that which has been previously recognized and acknowledged. Bridging the educational and healthcare systems is not an easy task yet these school nurses had found many ways in which to do just that, be the lone healthcare provider in a world of educators. The school nurse truly deserves the title of unsung hero of the healthcare system. Little research has been conducted about factors contributing to care

coordination for CSHCN by school nurses. This study fills a gap in knowledge about school nursing and raises questions for future research about the understanding, contributing factors and barriers to effective care coordination by school nurses for CSHCN.

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Appendices

Appendix A. Invitation letter to potential participants.

You Are Invited

To participate in school nursing research

The purpose of this research is to investigate the factors that impact school nursing care coordination of children with special healthcare needs.

The requirements for participation are:

Have experience with at least one care coordination activity for a child with special healthcare needs

Willing to be interviewed by a PhD candidate in nursing

Have 1 to 1 ½ hours of time to spend on the interview

Have an interest in participating in research

Interviews will be conducted at a time and place convenient for the participant

Telephone interviews are an acceptable alternative to a face to face meeting

All data collected will be kept confidential and no identifying information will be included in any report or data

If you meet these requirements and are interested in participating, please contact the nurse researcher,

Lynn Choromanski, PhD (c), RN-BC, CNM by e-mail at

chor0019@umn.edu or phone 763-218-2013

Any questions can be directed to this e-mail or phone or to the advisors for this project:

Connie Delaney (Delaney@umn.edu) or Bonnie Westra (westr006@umn.edu)

4-1-11

Dear Lead School Nurse or Public Health Nurse,

My name is Lynn Choromanski. I am a doctoral candidate at the University of Minnesota working on my dissertation. I am writing to you today with an invitation for nurses within your organization to participate in research on school nursing. I was a school nurse in the past and know the extraordinary work that school nurses perform. I currently work for Gillette Children's Specialty Healthcare in St. Paul, MN where we care for children with disabilities.

The focus of my research is on the experience of school nurses with care coordination activities for these special children. The research is qualitative in nature, asking questions, interviewing and analyzing the transcripts of the interviews. In addition a short demographic survey will be completed.

I am asking that you share this invitation with your staff. If they are interested in participating in this research please have them contact me. All my contact information is within this letter and invitation.

I look forward to working with Minnesota school nurses on this important topic. I hope to be able to share my findings at future school nursing conferences and in school nursing publications.

Sincerely,
Lynn Choromanski, PhD (c), RN-BC
University of Minnesota, School of Nursing Doctoral Candidate
chor0019@umn.edu
763-531-8356

Appendix B. School Nurses of Minnesota e-mail to members.

Lynn Choromanski

From: Mary Heiman <mary.heiman@mpls.k12.mn.us>

Sent: Friday, April 01, 2011 3:31 PM

To: SNOM Mailing List

Cc: Lynn Choromanski

Subject: LSN research: A chance for you to participate

Attachments: You Are Invited - Research flyer.pdf (see appendix A above)

Dear SNOM members,

The SNOM executive board has agreed to allow Lynn Choromanski, a school nurse researcher, to use our listserv as a means of recruiting research subjects. Lynn is a former school nurse, currently a PhD candidate at the University of Minnesota, School of Nursing. She has experience in school nursing and currently works for Gillette Children's Specialty Healthcare. Please consider participating in her research as it is a goal of NASN and SNOM to encourage participation in research focused on school nursing.

This research has been approved by the University of Minnesota IRB as an exempt study; a study with minimal or no risk to participants. This research involves 1 - 1 ½ hours of your personal time where you will be interviewed on the subject of care coordination for children with special healthcare needs (CSHCN). CSHCN is broadly defined and can include any student who has a healthcare need that you have organized or managed care for in your school; they do not need to be on and IEP or 504 plan.

Details of the research and contact information are included in the attached flyer.

Please consider this chance to participate.

Mary Bielski Heiman, RN, LSN, MS

SNOM President

Minneapolis Public Schools

612-668-0853, voice mail

Appendix C. Script for telephone contact with potential participants

1. Hello, my name is Lynn Choromanski. I am a PhD candidate at the University of Minnesota, School of Nursing. You responded to an e-mail request for individuals interested in participating in research on school nursing. This research is for my dissertation.

Decision Point: Do you have a few minutes to review the purpose and requirements for participation in this research to see if you would be interested in completing the interview and survey process?

If YES – then proceed on to section **2**

If NO – ask if I can reschedule a time to call back.

If YES, schedule a convenient time for the potential participant

If No, thank the participant for their interest and remove them from the list of potential subjects.

2. Thank you for taking the time to review the research study purpose and the requirements for participation in the study.

The purpose of the study is to investigate the factors that impact school nursing care coordination of children with special healthcare needs. Children with special healthcare needs are defined as children who is enrolled in an elementary, middle or secondary school in the State of Minnesota who have a chronic medical condition that require very frequent or daily school nurse contact, have health problems that require care coordination or management at school or children whose chronic medical condition makes them at higher risk for absenteeism.

Decision Point: Do you care for children with special healthcare needs as defined?

If YES – proceed to the section **3**

If No – thank the participant for their interest and remove them from the list of potential subjects.

3. This method involved in this research is to interview individual school nurses, asking them to describe their experiences with care coordination for children with special healthcare needs. You will be asked to describe a situation where you have had to coordinate care for a child and what worked and didn't work about that experience. There will be follow up questions to answer the study aims of this study. In addition a short demographic survey about you school and school district will be completed. Your identity and the identity of any children you discuss will remain anonymous. Your name will not appear in any data or reports resulting from the interviews.

Decision Point: Do you think you would be interested in participating in this research?

If YES – proceed to the section **4**

If No – thank the participant for their interest and remove them from the list of potential subjects.

4. The interview should take between 1 to 1 ½ hours. We would need to arrange to meet at a public place like a library or the interview can be completed by phone if you are not in the metropolitan Twin Cities area. At any time during the interview if you want to stop the interview, that is your decision. There are no negative consequences for ending the interview early.

Decision Point: Are you willing to participate in this research?

If YES – proceed to the section **5**

If NO - thank the participant for their interest and remove them from the list of potential subjects.

5. Arrange for a satisfactory meeting place and time based on the availability of the school nurse. Ask for their e-mail address to send an appointment reminder.

The call ends.

Appendix D. Semi-structured interview guide.

I would like to begin the interview with you telling me in your own words about an instance where you had to provide care coordination activities for a CSHCN in your school. Please remember to refrain from using the child's name; you can choose an alias if that makes it easier for you to tell the story. (Allow participant to complete the story)

While the story is being told, notes are being taken against the list of questions below. Areas that are not clear or have not been addressed will be the source of follow up questions: (see below)

1. What criterion do you use to identify CSHCN who might benefit from school nursing care coordination?
2. Please describe your role and responsibilities as a school nurse in coordinating care for CSHCN.
3. What information sources are available to you as a school nurse?
    a. What sources are the most valuable?
    b. Who provides the information needed for care coordination?
    c. What is your perception of the completeness and accuracy of the information?
4. What tools/ resources do you as the school nurse have at your disposal to coordinate care for CSHCN?
5. What tools/ resources would be helpful to school nurses to enhance care coordination for CSHCN?

6. What are the processes or methods in place to communicate the needs, plans and goals of care coordination activities for CSHCN?
7. What format does the plan of care take – Individualized Healthcare Plan (IHP), Emergency Care Plan (ECP), other?
    a. Is a formalized written care plan prepared?
        i. If a written care plan is not completed, why not?
    b. How do you communicate care coordination plans to members of the education team and family/caregivers?
8. How do helping relationships impact your ability as the school nurse to develop and implement care coordination plans for CSHCN?
9. List the factors that most facilitate you when planning and communicating care coordination activities.
10. List the factors that most inhibit you when planning and communicating care coordination activities.

Appendix E. Collection of Survey Data

In order to understand the context in which you work, I would like to collect some information about you and your school district. No identifying information will be gathered.

1. Do you practice at one ____ or more ____ school buildings?
2. If more than one, how many? _____ (numeric)
3. How many students are enrolled in your school district? _____ (numeric)
4. How many students are enrolled in your school(s)? _____ (numeric and an approximate count is acceptable)
5. Is your school(s) elementary _____ middle or junior ____ or high or senior high or alternative ____ school? (enter number that apply)
6. How many students in your school(s) qualify for special education services? _____ (numeric)
7. What percentage of students in your school(s) qualifies for the free or reduced lunch program? _____% (numeric)
8. Do you care for children with special healthcare needs (CSHCN) in your school(s)? ___yes ___no

11. Have you had experience with care coordination activities such as developing care plans, contacting outside providers or agencies on behalf of the student, contacting parents to arrange for supplies or medications for the student? ___yes ___no

Nurse participant personal demographic information:

____age ___ gender _____educational background

_____ years of nursing experience _____ years of experience as school nurse

_____years of experience as school nurse in this school district

Appendix F. Agreement to participate statement.

INTRODUCTION SCRIPT FOR INTERVIEW _____Subject Number

Thank you for your willingness to meet with me today. I just want to review with you some ground rules for the interview and confirm your willingness to participate. First, I want to tell you that we will be recording this session with a tape recorder and that a transcript of the session will be completed by a professional transcriptionist. To protect your identity, I will refrain from using your name in the conversation. Please also refrain from naming yourself, anyone you work with, your school or school district and any client you will use in an example.

This interview is expected to result in minimal or no risk to you. Please understand you may choose to stop the interview at any time and I will respect that. No negative consequences will come to you should you decide to decline to be interviewed.

- Do you agree to participate in this interview? If yes, proceed with the next section. If no, the tape recorder is stopped and the session concludes.