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**UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING**

**ROLE PERCEPTIONS OF SCHOOL NURSES
WHO WORK WITH MEDICALLY FRAGILE STUDENTS**

By

Cay Chapman Casey

**A dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
UNIVERSITY OF SAN DIEGO**

**In partial fulfillment of the
requirements for the degree
DOCTOR OF PHILOSOPHY IN NURSING**

May, 2002

Dissertation Committee

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Abstract

In 1999, the Supreme Court ruled that school districts were financially responsible to provide related services including nursing services, to medically fragile students. This decision applied to children attending public schools who have complex health problems and are tracheostomy dependent. The purpose of this grounded theory study was to explore role perceptions of eighteen school nurses caring for these children in classrooms. Six dimensions emerged from the data: *Promoting Family/ Nurse Connections*, *Adapting the Environment*, *Claiming Authority*, *"Standing Out There"*, *Striking a Balance* and *Experiencing Success*.

Promoting Family/Nurse Connections emerged as the central perspective, essential to implementing a plan of care. Solicited parental knowledge about individual student preferences and care routines helped contribute to a successful transition between the home and classroom. *Adapting the Environment* described the context in which the work of these nurses took place. Classroom challenges of limited physical space, lack of privacy, and inadequate specialized equipment were frequently encountered. School nurses faced the complexities of providing highly sophisticated nursing care to students with differing language capabilities, ethnicity, or health values. Implementing plans of care required continuing communication with numerous health care providers and multiple insurance payers. *Claiming Authority* described the in-depth clinical knowledge and technical expertise school nurses needed to manage students requiring respiratory support, artificial feedings, and urinary catheterizations in classroom settings. Nurses frequently functioned in collaboration with teachers, therapists, and members of the educational support team.

“Standing Out There,” described conditions of both fear and autonomy. Fear was heightened by a sense of being the only nurse, and having limited emergency equipment on site or assistance from trained medical personnel. Positive outcomes resulting from independent nursing decisions reinforced a sense of autonomy. *Striking a Balance* described the professional nursing judgment involved in conducting physical assessments, determining health priorities and balancing these with each student’s educational program. *Experiencing success* was a consequence of respecting students’ intrinsic values of perseverance and determination, facilitating successful student transitions, and effectively integrating facets of the nursing role. Further research questions regarding medically fragile children in classrooms were generated, and areas of ethical conflict and health policy reform were identified.

Dedication

**To my grandchildren that you may someday know
Nursing offered hope and opportunities to grow
Faith and friends helped me navigate this stream
These ten years have fulfilled a lifetime dream
This PhD proves that you can do this too
Dream, hope, and grow knowing Nana's love for you
Peace.**

Acknowledgments

The completion of my doctoral dissertation would not have been possible without the love and support of so very many people and two special canines, Seamus and Abby. Space permits the mention of only a few individuals but there are so many family members and friends that I will always hold in deep appreciation and eternal gratitude.

To my beloved spouse and very best friend, John Michael Casey, M.D., I can only say this would have not been possible without you. Your unending and tireless listening ears and reassuring hugs gave me the impetus to carry on and persevere throughout these past ten years. I love you and I thank you.

To my role model and Doctoral Committee Chairperson, Dr. Patricia Roth, you remain the kindest and most empathic mentor any student can ever have. Thank you for your constant encouragement, words of wisdom, and belief in my ability to complete this endeavor. To Dr. Mary Jo Clark, Doctoral Committee Member, I remain indebted to you for your editorial diligence and focused determination. To Dr. Susan Instone, Doctoral Committee Member, I am grateful to you for your professional wisdom and keen insight in the areas of school nursing clinical competence.

To my children, Timothy Michael Casey, J.D., Bridget Casey Vedder, M.D., Kevin Matthew Casey, M.D., and Anne Casey Clark, P.T. and to my grandchildren, Madeleine, Emma, Liam, and Michael and to those yet to be born, I thank you for this opportunity to dream, to hope, and to grow. I humbly dedicate this work to you in grateful appreciation for all the joy and all the love you have given to me.

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Chapter I: Focus of the Study

Within the past decade, advances in medical science and vast improvements in assistive technology have contributed to an increase in the number of children that survive prenatal complications and complex congenital diagnoses. Today these “surviving miracle” individuals are entering the doors of public schools and are demanding their rights to a free and appropriate public education. The multidimensional complexities of meeting the health needs of medically fragile students in these settings represent a daily challenge in the professional life of a school nurse. The perceptions of school nurses’ professional role identities and role integration in working with these children formed the focus of this research.

The praxis of professional school nursing is embedded within the state and federal statutes regarding public education, and the translation and application of federal requirements at state and local levels remains an ongoing challenge (Watkins et al., 1998). Schools are faced with the challenges presented by children with special needs because the law requires that all children receive free and appropriate public education within a least restrictive environment (Esperat, Moss, Roberts, Kerr, & Green, 1999). The health-related needs of these students must be met so that their civil and educational rights can be met. Medical needs and educational rights are coexistent with each medically fragile student and affect the professional role of the involved school nurse. The United States Supreme Court rendered a decision on March 3, 1999 that reverberated throughout the nation's public school system. This legal ruling required that Local

Educational Agencies (LEAs) be held responsible for providing the medical personnel necessary to permit a medically fragile student to attend a public school (Greenhouse, 1999). Prior to this time, there had been considerable contested debate as to what agency would assume the cost of such personnel--the family, health care insurer, or public school district (Barkoff, 1998). This legal decision directly involved the schools and the students referenced in this study.

The school district in which the study occurred had close to 10% of its total population enrolled in special education. Medically fragile students accounted for less than 1% of this population; yet represented one of the most expensive elements of total educational expenditures. Profound advances and emphasis on perinatal research had contributed to this reality. The past decade of medical research within the specialties of obstetrics, neonatology, and pediatrics has generated not only an increase in the number of students, but also resulted in an ever-increasing complexity in their medical and educational needs (Griffin, Wishba, & Kavanaugh, 1998; Reynolds & Mann, 1996; Singer, Toyoko, Lilien, Collin, & Baley, 1997).

The number of children with health-related disabilities in society and in classrooms has greatly increased due to medical advances and reduced mortality rates among premature infants (Koenning et al., 1995; Miller, Rice, DeVoe, & Fos, 1998; Picuch, Leonard, Cooper, & Sehring, 1997). It has become necessary to integrate needs for sophisticated health care into Individualized Educational Programs (Esperat et al., 1999). Without assistance with health needs provided in the educational setting, children with disabilities would be forced to return to isolated and segregated educational settings (Bartlett, 2000).

The mere presence of medically fragile students within a public school setting has brought about a myriad of legal, medical, and educational challenges. Recent publications regarding medically fragile students have included the following: (a) legal court rulings mandating nursing services be provided and paid by the school district (Bartlett, 2000; Greenhouse, 1999; LRP 1998; Simpson 1999); (b) medical research indicating the need for health care coordination and parent-professional collaboration (Gleason & Finkelstein, 1998; McClain & Bury, 1998; Ziring, Brazdziunas, Cooley, & Kastner, 1999); and (c) educational research focusing on technological trends within the school setting (Bartlett, 2000; Thomas & Hawke, 1999). All have direct implications for the professional role as performed by the school nurse (Bradley, 1997; Myers, 1998; Newcomer & Zirkel, 1999).

Although the literature abounds with statutory and legal decisions regarding the implementation of special education services, there remains a paucity of nursing research regarding the integration of the professional school nurse role with medically fragile students. Multidimensional components of this phenomenon remain to be studied. For this reason, the current study explored the role perceptions of school nurses to elucidate the ongoing dynamic processes involved in their work with medically fragile students.

Purpose of the Study

The study explored the expanded role perceptions of the school nurse who work with medically fragile students within a public school setting. Discovery of school nurses' interpretations of meanings attached to their role provided an initial step in understanding the multifaceted complexities encountered by these health care professionals.

Lines of Inquiry

The study explored the role perceptions of school nurses engaged in meeting daily health care needs of medically fragile students. Data were generated from their perceptions, beliefs, values, feelings, and professional strategies to develop a grounded theory. The following lines of inquiry guided the study:

1. What are the role perceptions of school nurses regarding their work with medically fragile students?
2. Under what conditions and in what context do school nurses work with medically fragile students?
3. What are the barriers to/facilitators of successful role implementation?
4. What do school nurses perceive as successful outcomes with medically fragile students?

Method

Since little is known regarding the perceived realities of school nurses as they care for medically fragile students, the qualitative method of grounded theory, including dimensional analysis, was selected. The methodological procedures of grounded theory provide a multidimensional understanding of the social and psychological processes of a phenomenon and the conditions under which it occurs (Strauss & Corbin, 1998).

During the comparative analysis, a working theory emerged that helped to explain the processes under study. Dimensional analysis was utilized to further explicate the interactions delineated in or derived from the interviews. Dimensional analysis broadens the concepts of grounded theory by attempting to describe the constant, dynamic interactions that occur in complex social phenomena (Kools, McCarthy, Durham, &

Robrecht, 1996). It was anticipated that the methodologies would provide a multidimensional understanding of the social and psychological processes experienced by the participants.

Philosophical Underpinnings

The philosophical underpinnings of dimensional analysis lie within symbolic interactionism (Kools et al., 1996). Blumer (1969) presented three basic premises or assumptions of symbolic interactionism: (1) humans behave differently based on the underlying meanings objects, people, and everyday events have for them; (2) these meanings are derived from or arise out of interactions with others; and (3) meanings are used and modified in an ongoing process of interpretation. All human behavior is envisioned by Blumer as the result of a “vast interpretive process in which people, singly or collectively, guide themselves by defining the objects, events, and situations they encounter” (p.132).

Schatzman’s (1991) method of dimensional analysis is built on the premises of Blumer’s theory of symbolic interactionism. The interpretive process inherent in symbolic interactionism is termed “natural analysis” and was theorized by Schatzman as a normative cognitive process used by individuals to interpret and understand problem situations, experiences, and phenomena (Kools et al., 1996; Schatzman, 1991). Through the learning of language and the ability to engage in social interaction, people refine their ability to perform natural analysis. Natural analysis provides “individuals with a schema they subsequently use to structure and analyze the intricacies of phenomena of ordinary life, and scientific analysis is an extension of natural analysis” (Kools et al., 1996, p. 314).

Dimensionality provides an extension of a person's natural analytic processes when recognition and/or recall fail to provide understanding of an experience or event. Dimensionality is a cognitive attribute that allows an individual to derive meaning through interpretation of different attributes of a phenomenon or situation (Kools et al., 1996; McCarthy, 1991). These attributes or abstract aspects of a constructable reality are referred to as dimensions (Schatzman, 1991).

It was the philosophical framework of symbolic interactionism that gave meaning and significance to the findings extrapolated from the data analysis. Relevant dimensions pertinent to the conditions and context of role perceptions experienced by school nurses provided enhanced awareness and new knowledge of social interactions encountered within the public school setting.

Significance of the Study

Medically fragile students who attend public school classrooms present a myriad of complexities to educational and health care professionals involved with their care. School nurses provide daily assistance in meeting the challenges of their students' medical needs, educational mandates, and legal rights. These complex challenges that occur on a daily basis significantly affect the professional practice of the school nurse. Little is known about the perceptions, beliefs, values, feelings, and strategies involved in the daily practice of nurses caring for medically fragile students within the public school setting. This study seeks to provide first-hand knowledge of what is truly involved in assuring the students' health and safety. The school nurse is the one professional who attempts to facilitate the transition from home to school and keep in mind the medical needs as well as the educational rights of these students. The role of the school nurse

presents an interesting and intricate matrix of responsibilities. The health and wellness of medically fragile students remains a top priority. Assurances of mandated educational rights to a free and appropriate education are elements superimposed on the traditional caregiver role. Therefore, it is important to obtain more information regarding nurses' experiences and to specifically identify the facilitating or hindering actions, conditions, and contextual dimensions that affect their professional role.

This study represents a contribution to nursing research regarding the lived experiences of school nurses caring for medically fragile students within the public school environment. Since much of the current literature involves the care of medically fragile students within neonatal intensive care units and hospital environments, this study will focus on the role of nursing within the community setting of public schools. By identifying the complicated dynamics of their professional roles, new intervention strategies, adaptive environmental changes, and innovative health policy revisions may be implemented to promote effective school nurse outcomes. This knowledge will influence nursing education, nursing practice, and ultimately legislative initiatives.

With the enactment of the Civil Rights Act, the Individuals with Disabilities Educational Act, and other legislative mandates children with special needs have now entered local public school classrooms. With their entrée, schools are encountering a plethora of extended educational rights and complex medical diagnoses that influence the conduct of the educational endeavor. Medical research and innovative life-sustaining technologies have produced medical, educational, and legal challenges far beyond the imagined scope of school district responsibilities. Professional school nurses are expected to meet these challenges on a daily basis. School nurses represent an important

link between home and school, between medical concerns and educational rights, and between realistic and unrealistic expectations. Knowledge from these parameters contributes to a successful school experience for everyone connected with these students. This study seeks to explore a holistic perspective of the professional role of school nurses working with medically fragile students and to facilitate the formation of a theoretical model that could be tested in subsequent research. This study seeks to contribute not only to the knowledge base of nursing but also to the fields of education and policy development.

Chapter II: Literature Review

The presence of medically fragile students is a reality in many classrooms in today's public schools. As the number of these students increases and their medical conditions become more complex, school nurses have additional responsibility for their care. This literature review focuses on three areas that directly affect the professional role of school nurses: (a) special education—its history and current mandates (b) medically fragile students—changes over time and current rights and (c) school nursing and professional role development.

Special Education

As defined by #34 of the Code of Federal Regulations, Section 300.17, special education is

specially designed instruction, at no cost to the parent, to meet the unique needs of a child with a disability, including instruction conducted in the classroom, in the home, in hospitals, and institutions, and in other settings; and instruction in physical education. (Smith & Luckasson, 1995, p.6).

The evolution of special education has been a slow process as societal attitudes have changed from an isolationist approach (keeping those with medical and other problems separate from the mainstream population) to a more inclusive acceptance of those with special needs.

Early efforts to educate special students. Early records of special education began with the work of French physician Jean-Marc-Gaspard Itard. In 1799, Itard found a

young boy (later named Victor, the Wild Boy of Aveyron) living wild in the French woods. Itard educated Victor to speak, eat, walk upright, and interact with others using new educational principles (called aims), then recorded his techniques for others to follow. Itard believed that the right environmental conditions would humanize Victor or any similar child (Elias, 1995). Itard's work was continued by his student, Edouard Seguin, who published the first special education treatise regarding the needs of children with disabilities, entitled "The Moral Treatment, Hygiene, and Education of Idiots and Other Backward Children" in 1846 (Smith & Luckasson, 1995). Seguin later moved to Syracuse, New York where he founded the first state residential institution with an educational program for mentally retarded persons (Elias, 1995). Other early efforts to educate special children included a residential school for the deaf founded by Rev. Thomas Gallaudet in Connecticut in 1817 with an appropriation from the state legislature; Kentucky's first state school for the deaf established in 1823; a school for the blind established by Dr. John Fisher in 1829; and the first school for the blind and deaf founded by Dr. Samuel Gridley Howe in Boston in 1831 (Sigmon, 1987). However, except for these isolated residential institutions, there was virtually no formal special education in the United States until the latter half of the 19th century.

In 1864, the federal government first implemented special education when President Lincoln signed a law establishing Gallaudet College as an institution of higher education for the deaf (Weintraub & Abeson, 1974). At the public day school level, the first school for the deaf was established 5 years later in Boston; public school classes for retarded children in Providence, Rhode Island were implemented; and classes for the physically handicapped in Chicago were established (Howe & Miramontes, 1992).

Special education classes in regular schools were first developed in Cleveland in 1878 and in New York in 1898 (Smith & Luckasson, 1995). Although efforts in special education signaled a significant change in public attitude, the movement was confined to self-contained classrooms with relatively little socialization with other "regular" children. The stigma of being different was reinforced by society in general, and this situation did not change until the courts, legislatures, and other policy making bodies began to establish new standards for the education of all children.

According to Ballard, Ramirez, and Weintraub (1982), only 12% of all children and youth with disabilities received special education as late as 1948. By 1962, only 16 states included "educable" mentally retarded children under mandatory school attendance laws (Smith & Luckasson, 1999).

The current phase of special education that Sigmon (1987) referred to as the "desegregation phase" began in the 1950s when influential people began looking into the efficacy of self-contained (segregated) special education classes. Public awareness of children with special needs was fostered in the 1960s because President Kennedy's sister was institutionalized due to a mental condition (Allen & Allen, 1979).

Medical practitioners who were motivated by humanitarian values and concerns for those considered less fortunate supported a new social philosophy that promoted the following tenants:

Humanistic values that recognize the dignity of persons and their need for a certain degree of independent development continue to spur advocates of special education. More recent efforts have been grounded in the legal and moral rights of

dignity, courtesy, and respect, as well as equal opportunities to become productive and socially acceptable human beings (Elias, 1995, p. 226).

The institutionalization stage of special education has given way to the development of day schools, special classes, and public school involvement (Sigmon, 1987).

Perpetuation of a free government provided motivation to sustain the drive for special education within the school setting as noted in the following quote fact:

An ignorant people may be governed, but only educated people can govern themselves. Knowledge and learning as well as virtue generally diffused throughout the community are essential to the preservation of a free government and of the rights and liberties of the people. Hence for the protection and perpetuation of free government, State legislatures inserted within their State constitutions the provision that established and provided for the maintenance of an efficient and uniform system of public schools, free to all children of the State within the school age. (Wilcox, 1974, p. 33)

Legislation. Legislation has played a key role in extending the right of free education to children with physical handicaps. From 1827 through the early 1900s, federal laws specifically addressed blind and deaf communities. However, a major change occurred on October 17, 1962, when the Public Health Service Act became public law (PL 87-838), establishing the Institute of Child Health and Human Development to oversee the welfare of children in the United States. The Elementary and Secondary Education Act (ESEA) (Federal Law 89-313) provided funds for education of handicapped children in state-operated or state-supported schools (Ballard et al., 1982, p. 95). Between 1966 and 1974, a series of federal laws focused on children with disabilities

and the services they needed and paved the way for the most comprehensive and significant legislation regarding education of handicapped children: The Education-for-All Handicapped Children Act (EHA) of 1975 (PL 94-142), which was renamed the Individuals with Disabilities Education Act (IDEA) in 1990. PL 94-142 was significant because it applied to all children and youth 3 to 21 years of age. In addition to denoting specific categories of impairment, it had seven major provisions:

1. Free appropriate public education (FAPE) at no cost to the student and family, with all costs covered by the states and federal government.
2. Notification and procedural rights for parents including access to the child's records, written notification of school evaluations, and legal counsel.
3. Identification and services to all children, requiring states and schools to locate all eligible students.
4. Related services including developmental, corrective, and other support services as needed (e.g., transportation, speech pathology, psychological services).
5. Individualized and nondiscriminatory assessments, including evaluations and tests by trained professionals.
6. Individualized education program (IEP) plans, including a written collaborative statement agreed upon by the teachers, counselors, participating agencies, parents, and child.
7. Education in the least restrictive environment (LRE): To the maximum extent possible, children with disabilities are to be educated with children

without disabilities, with separate classes only “when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily” (Smith & Luckasson, 1995, p. 23)

A 1993 report from the U.S. Department of Education to Congress estimated that almost 5 million children through age 21, or 7.3% of all U.S. children, participated in special education programs under IDEA (Smith & Luckasson, 1995). In its report, the Department of Education designated 12 special education disabilities, including the estimated percentage of special education students designated with that disability (see Table 1). However, Smith and Luckasson (1995) warned that “the names we use to describe persons with special needs can influence the way people think about these individuals and their abilities” and these labels can “also affect how individuals with special needs regard themselves” (p. 8).

The American Disabilities Act of 1997 and the IDEA represent America’s primary special education laws. The IDEA dictates that a partnership exists between school districts and parents of students with disabilities. Through IEP recommendations, all parties work together to create the best opportunities for students with special needs.

Major court decisions. In the early 1900s, a change in public policy began to occur. For example, in 1911, New Jersey adopted the first special education mandates, Minnesota established special education certification requirements by 1915, and Pennsylvania provided for cooperative agreements by school districts for special education in 1919 (Ballard et al., 1982). Further, three court cases have had major impact

Table 1

Percentages of Special Education Population by Disability Classification

Disability	Special Education Population Percentage
Special Learning Disabilities	49.9
Speech or Language Impairments	22.2
Mental Retardation	12.3
Serious Emotional Disturbances	8.9
Multiple Disabilities	2.2
Hearing Impairment	1.3
Other Health Impairments	1.3
Orthopaedic Impairments	1.1
Visual Impairments	0.5
Autism	0.1
Traumatic Brain Injury	0.0
Deaf/Blind	0.1

Note. From "Fifteenth Annual Report to Congress on the Implementation of the Individuals with Disabilities Act," by U.S. Department of Education, 1993, p. A-1.

on ensuring that children with special needs have access to public education (Smith & Luckasson, 1995).

First, *Brown v. Board of Education* (1954) ended racial segregation in schools, and was later extended to forbid exclusion based on disability. In this case, the U.S. Supreme Court reminded states and their localities of the importance of education to the individual when it decreed:

Today, education is perhaps the most important function of state and local governments. In these days it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. Such an opportunity, where the state has undertaken the right to provide it, is a right that must be available to all on equal terms. (Ballard et al., 1982, p. 13)

In *Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania* (1972), the case was resolved by a consent agreement specifying that the state could not apply any law that would postpone, end, or deny mentally retarded children access to a publicly supported education. Furthermore, the state was required to identify all school-aged children with mental retardation who were excluded from public schools and to place them in free programs of education and training appropriate to their capacity. In addition, it was agreed that it was highly desirable to educate these children in programs most like those of non-handicapped children. This decision guaranteed special education for mentally retarded children (Ballard et al., 1982).

Mills v. Board of Education of the District of Columbia (1972) was initiated by parents and guardians of seven District of Columbia children against the District's Board of Education on behalf of all out-of-school children with disabilities. This class action

suit was resolved by a judgment against the school board and resulted in a court order that the District of Columbia must provide all children with disabilities, regardless of the severity, with a publicly supported education (Ballard, et al., 1982). According to Weintraub and Abeson (1974), these right-to-education cases initiated a quiet revolution.

Other court cases have challenged or extended aspects of the IDEA, but this piece of legislation remains at the heart of special education today. However, conflict continues to surface due to misinterpretation of federal statutes and regulations (Council for Exceptional Children, 1997; Gross, 1999; LRP Publications, 1998). In fact, Newcomer and Zirkel (1999) identified 414 published court cases involving special education since 1975. The investigators found documented results indicating that scarce financial resources were increasingly diverted to court expenses and attorneys fees. Further, Kopelman (1996) found ethical dilemmas faced by special education teachers, and Thomas and Hawke (1999) cited a lack of protocols and procedures regarding health care services as a major contributor to conflict and misinterpretation within special education. Unfortunately, many court cases clearly demonstrate a steady struggle to extend legal rights to children with special needs. Specifically, they reflect a greater awareness of the importance of education to the life and minds of all children, the inherent inequality of separate education, and advocacy efforts on behalf of persons with disabilities drawn from the context of the Civil Rights Movement (Abeson & Zettel, 1974).

Most recently *Garrett v. Cedar Rapids* (1999) required educational agencies, including school districts, to provide skilled nursing personnel as a related service to ensure the free and appropriate public education of medically fragile students within a

least restrict environment. At the school level, the professional health care contact for these students is most often the school nurse.

The Medically Fragile Student

The number of children with health-related disabilities attending public schools has increased throughout the last decade (Koenning et al., 1995; Miller et al., 1998; Piecuch et al, 1997). For those involved with schools, the results of advanced life-saving measures have presented an ever-increasing complexity of students' medical and educational needs. For those involved in special education, children with complex needs may be referred to as "medically fragile students." Vergason (1990) defined the medically fragile student as "an individual who has a chronic or recurrent physical or psychiatric disorder that requires medical services to be closely available or constantly present" (p. 106). According to Patterson, Jernell, Leonard, and Titus (1994), two criteria differentiated medically fragile students from other students: (a) they were dependent on a medical device to compensate for the loss of a vital body function and needed substantial ongoing nursing care, and (b) if equipment was not needed, they still required skilled nursing care. Reynolds and Mann (1996) expanded that definition as follows:

The medically fragile student requires monitoring by the teacher during the school day in order to ensure that all of the body's physical systems are stable. Medically fragile students are different from each other. They have different needs, energy levels, and potentials. One of the most frequently observed types of medically fragile student is one who requires the use of a ventilator to facilitate breathing. Other health problems that may label a child medically fragile include chronic

disease, terminal conditions, post-surgery recovery, apnea, severe depression, cardiovascular problems, and kidney dysfunction (p. 1012).

In 1999, Miles, Holditch-Davis, Burchinal, & Nelson referred to a medically fragile child as:

one who has a life-threatening chronic illnesses such as bronchopulmonary dysplasia, severe gastrointestinal malformations, neurological anomalies, complex congenital heart disease, and multisystem syndromes...They experience extended hospitalizations and/or frequent rehospitalizations and long periods of dependence on technology for survival (p. 129).

Within the school environment teachers are definitely affected by the presence of medically fragile students. The seminal work of Izen and Brown (1991) revealed confusion and anxiety surrounding health care responsibilities of educators with medically fragile students in their classrooms. Silver (1999) confirmed the heightened anxiety levels of school staff when a perceived emergency regarding the health care of medically fragile students was relegated to educational personnel

In a popular teacher education textbook, *Introduction to Special Education* by Smith and Luckasson (1995), those preparing to become teachers gained but a glimpse of their future responsibilities regarding special students. Unfortunately, the book gives minimal advice on how teachers can utilize the expertise of other health professionals, especially the school nurse. Obviously, the special needs of these students constituted a significant impact on the educational process as viewed through the teacher's perspective (Watkins et al., 1998).

Life-saving and life-sustaining technologies are constantly being improved, and now allow children to move from the hospital to home and into the community, including schools. Premature, sick, low birthweight, and high-risk neonates now survive (Capen & Dedlow, 198; Miles, Holditch-Davis, Burchinal, & Nelson, 1999; Piecuch et al., 1997; Singer et al., 1997; Weber, 1998), but all too often they remain technology-dependent (Catlin, 1999). These students required daily, ongoing care, and monitoring by trained personnel within a public school environment. More importantly, the trained personnel must be provided by the public school in order for the medically fragile students to obtain a free and appropriate public education (Greenhouse, 1999). It is often the school nurse, who is accountable on a daily basis, for the competent and successful provision of medically fragile students' health care, including the availability and proper use of any required medical equipment.

The School Nurse and Professional Role Development

Throughout history the care of people with special needs has varied according to societal mores. From the time of ancient Greece and Rome, handicapped individuals were often kept as jesters for entertainment, and many people experienced despair, distaste, and outright ostracism from daily human interactions (Allen & Allen, 1979; Elias, 1995). Those considered “feeble-minded” were labeled as “morons, imbeciles, and idiots” as well as “holy innocents and special children of God” (Allen & Allen, 1979, p. 25). Consequently, social isolation preceded the establishment of residential schools and segregated institutions, which then imposed total separation from families and communities. In many of these institutions, nurses were the primary daily care-givers.

Changes during the 1900s. American nursing first moved into the public schools in 1902 when Lillian Wald established the Henry Street Settlement in New York City. As an experiment, she transferred nurses from Henry Street and placed them into four city schools. Her goal was to determine if nurses working in the schools could reduce absenteeism caused by communicable diseases. The first nurse in Wald's experiment was Lina Rogers, who began to routinely examine students for early sickness exclusion. As a result, the spread of contagious diseases abated. Rogers then expanded her role by visiting selected children in their homes to teach proper methods of care. Because this experiment was successful, the concept of school nursing spread (Wold, 1981).

During the 1920s and 1930s, the school nurse's role expanded through three phases: medical inspection, medical examination, and health education (Bullough & Bullough, 1990). In the first phase, medical inspections were performed with the school physician or independently to control the spread of contagious diseases. In the medical examination phase, the school nurse assisted the school physician to identify physical defects and disability limitations in students. In the third phase, school nurses began to implement integrated health education programs to prevent disease, with short talks to students regarding cleanliness, good nutrition, dental hygiene, proper exercise, and adequate sleep.

During the 1940s, school nursing was identified as public health care. Since many defects found in children entering school could have been prevented or minimized with earlier recognition and intervention, the focus of the school nurse was expanded into students' homes to address the needs of all family members, including infants and

preschoolers (Wold, 1981). The need for coordinated community services was evident, and school nurses were encouraged to fill the void.

By the 1950s, additional responsibilities for vision and hearing screening, hygiene inspection, first aid treatment, and referrals to family doctors became common (Jones, 1979). In addition, a paradigm shift occurred as health education replaced the detection of physical defects as the nurse's primary focus. School nurses were now expected to collaborate with the classroom teacher and school administrator as part of a health team. No longer was the nurse seen as an individual, but as part of a team with emphasis on illness prevention and health promotion (Wilson, 1959).

In the 1960s, liberal government initiatives introduced many new health and welfare programs that affected school nurses. The concept of the school health team was broadened to include the expertise of psychologists, counselors, health teachers, and social workers. During this time, increased enrollments in special education programs occurred and more handicapped children were educated in public schools. Concurrently, drug and alcohol use/abuse was prevalent among young people and their needs also required attention. With fiscal restraints facing many school districts, school nurses became a primary target for personnel reductions (Wold, 1981). Consequently, role confusion, diffusion, and strain characterized the school nurse role during these tumultuous years.

By the 1970s, chemical dependency had become a critical health problem that demanded attention in school health programs. Experimentation with sex, alcohol, and other chemicals created new problems related to delinquency, sexually transmitted diseases, and adolescent pregnancy. As a consequence, health supervision, including

guidance for pregnant minors became part of many school health programs (Wold, 1981). While school nurses played a central role in dealing with wider health issues, they also advocated for positive adaptations for special handicapped students and inclusion with non-impaired children in regular classrooms (Fisher, Pumpian, & Sax, 1996).

With the passage of the IDEA, the school nurse was recognized as an integral player on the student's educational team. For the first time in U.S. legislative history, the following statement was included:

Furthermore, the Committee recognizes that there are situations that merit the presence of a licensed registered school nurse in the IEP team. The Committee also recognizes that schools sometimes are assumed responsible for all health care costs connected to a child's participation in school. The Committee wishes to encourage, to the greatest extent practicable and when appropriate, the participation of a licensed registered school nurse on the IEP team to help define and make decisions about how to safely address a child's educationally related health needs. (Council for Exceptional Children, 1997, p.23)

School nursing conflict. As school nurses advocated on behalf of special students, conflicts arose for two main reasons: (a) the school nurse's role was related to an educational setting and (b) the ways in which nurses performed their roles were planned and largely managed by school officials whose orientation was outside the realm of the nursing profession (Regan, 1976). Hawkins (1971) explained the problem as follows:

School nurses performed tasks outside the context of healer and patient, with no clear professional guidelines, under non-medical norms, and with goals and means for achieving them largely divorced from the basic model of nursing. The

school nurse was expected to provide guidance in poorly defined areas, to coordinate activities of which he/she was only vaguely a part, and to cooperate in health education on terms dictated largely by others. (p. 746)

Oda (1979) added supportive commentary with the following statement:

There is a gap between educational preparation and practice setting; there are work setting differences; there is a wide age range of client populations; and there is the necessary variable in the school nursing role that results from the unique interactions of each school nurse and the specific school setting. (p. 498)

These demands place a great deal of pressure on the school nurse at a time when there is a shortage of qualified nurses (Chappell, 1998). As a result, nonqualified personnel are often employed to perform mandated specialized health care procedures in many school districts, but the onus of responsibility has not been lifted from the school nurse's job.

School nurse role. Professional literature concerning school nurses and medically fragile students has largely focused on health policies, transitional services, and personal qualifications. Oda (1979) advocated the development of a specialized role for school nurses and recommended role identification, role transition, and role confirmation as critical to the establishment of school nursing as a specialized and distinct specialty.

Role identification referred to role purpose and its clarity and articulation being based on a philosophy of practice. Nurses need to know what they will do as well as what they will not do, why they will do it, and when they will expect to achieve their goals to a certain degree. Role transition involves interactions that are guided by goal direction or movement toward the objectives of the nurse-defined role.

The interchange of perceptions must be a mutual process...The ultimate goal is to

create a role fit between what the role definer or specialized nurse feels is appropriate and what others in the work setting view as appropriate. Role confirmation is achieved when nurses receive recognition and support for their defined role and are permitted a high degree of autonomy. Evidence of role confirmation is when coworkers and superiors accept the role and include the nurses in work activities that make optional use of their expertise (p. 508).

New specialized education programs focused on the concept of a school nurse practitioner and paved the way for primary care procedures to be performed in the actual school setting (Igoe, 1980). Further, health assessment, maintenance, and management skills were emphasized in order to add quality, availability, and continuity of health care for children (Silver, Igoe, & McAtee, 1976).

In 1994, Hootman defined the numerous roles of school nurses as:

- Collaborator with federal, state, school, and community agencies, and health care provider for families to resolve health concerns.
- Catalyst for health education.
- Resource person linking students and families with other health and community services
- Clinician for students presenting illness and injury concerns and monitoring students with ongoing health care issues that may affect their learning abilities and/or safety in school
- Case manager of students with special needs.

Research has also shown that the daily care of medically fragile students is a formidable challenge for teachers. However, it is the school nurse who is responsible for

direct medical care at all times while the child is at school. Court rulings and federal mandates require that nursing services be provided for medically fragile students (Bartlett, 2000; LRP Publications, 1998; Simpson, 1999), but the complexity of their medical needs has created a much greater professional challenge for school nurses (Bradley, 1997; Myers, 1998; Newcomer & Zirkel, 1999). This challenge is added to responsibilities for mandated health screenings, health education, and health promotion for all students. Further, varied responsibilities, numerous roles, and complicated caseloads represent an inordinately intense and profoundly complicated professional challenge (Periad, Knecht, & Birchmeier, 1999).

In 1995, Bonaiuto explored experiences of school nurses giving care to students who depended on medical technology. Bonaiuto found an ever-increasing need for nursing competence regarding parenteral nutrition, feeding tubes, and extracorporeal oxygenation. Other researchers have also explored the role of the nurse educator, nurse case manager, and nurse health care coordinator (Bradley, 1997; Larter, Chernick, Maire, & DuBois, 1999; Ziring et al., 1999). Chan and Filippone (1998), Heaman (1995), and Weber (1998) supported a well-defined, organized, and multidisciplinary program of health care as an integral part of the total special education process. Parette, Bartlett, and Holder-Brown (1994) proposed a collaborative approach between educators and school nurses for medically fragile children to ensure the administration of safe and effective services. A few years later, McClain and Bury (1998) extended this collaboration to include parents, medical staff, social workers, specialized therapy providers, and education personnel involved with the health and welfare of students while attending school.

Cohen (1999) described the importance of intact health care policies and procedures regarding community and school transitions. He was especially concerned with how school nurses collaborated with other health care professionals and student families. In addition, Cohen understood that these collaborative efforts were critical components to ensure a medically fragile student's successful entry into school and community environments.

Although the responsibilities of school nurses have changed over the last century, their commitment to the welfare of all students has remained firm. Because legislation and court decisions have extended the rights of students to obtain public education, parents remain strong advocates and teachers work to create a positive learning environment for students. School nurses provide a unique and critical component regarding students' health concerns and safety. Their participation in a student's individual educational program represents an awareness of health and safety issues within the school environment. Although conflicts have arisen in the wake of greater levels of responsibility, today school nurses actively participate as part of the IEP team to ensure that medical concerns of students are addressed. Thus, an exploration of perceptions of the professional school nurse role by those individuals who are currently working with medically fragile students represents an attempt to heighten awareness of these realities. Such realities, if not known, cannot be valued or appreciated. Such awareness remains an important entity and the impetus behind this research endeavor.

Chapter III: Methodology

The intent of the study was to develop an emerging theory regarding school nurses' perceptions of their professional role in the daily care of medically fragile students in public school environments. Symbolic interactionism provided the philosophical basis for seeking an understanding of their roles and interactions. Further, grounded theory represented the methodological process that has its philosophical foundation in the tenets of symbolic interactionism and a focus on human behavior and the social world (Blumer, 1969).

Symbolic Interactionism

Proponents of symbolic interactionism view behavior as determined by the meaning of events that occur in natural or everyday settings. Nothing has inherent meaning or value; meanings are created by people as a result of their social interactions (Chenitz & Swanson, 1986). Value and meanings are subject to redefinition as a result of interactional experiences, and the reality of the experience becomes dynamic rather than static (Baker, Wuest, & Stern, 1992). From a symbolic interactionist viewpoint, the meaning of an event must be understood from the participant's perspective (Chenitz & Swanson, 1986). Behaviors must be observed in context to be understood and have meaning (Bowers, 1988; Chenitz & Swanson, 1986).

Grounded Theory

Grounded theory seeks to discover the derived meaning, contextual conditions, and interactional processes that surround a phenomenon from the participant's perspective (Strauss & Corbin, 1990, 1998). This methodology emphasizes the manner in which people view their circumstances, involved interactions, and how processes evolve and change (Bowers, 1988). Behaviors must be observed in context to be understood and have meaning (Bowers, 1988; Chenitz & Swanson, 1986; Hutchinson, 1993; Wilson & Hutchinson, 1991).

Grounded theory utilizes a process of inductive reasoning. A systematic set of techniques and procedures of analysis are used to discover a theory based or grounded in substantive data regarding the human interactional experience. Abstract concepts and propositions are derived from the words and statements of participants. Data reflect related themes derived from the participant's responses, emerging concepts, and relationships between these ideas.

Grounded theory generates new theories, contributes to new areas of research, or offers new approaches to old problems (Chenitz & Swanson, 1986; Hutchinson, 1993; Stern, 1985). During the interactional process, individuals engage in role-taking, accepting the perspectives of others, and creating their own realities that in turn shape actions (Wilson & Hutchinson, 1991). The truths that become evident are subject-oriented and defined rather than researcher-devised (Sandelowski, 1986).

Dimensional Analysis

Grounded theory is further enhanced in the data analysis process by the methodology of dimensional analysis (Schatzman, 1991). Dimensional analysis enables

the researcher to discover a person's interpretations and derive meanings from various phenomena within his or her social world (Robrecht, 1996). Dimensionality is a cognitive attribute (dimension) people use to derive meaning from a phenomenon or situation. Three distinct phases of this method of data analysis include designation, differentiation, and integration (Kools et al., 1996; Schatzman, 1991).

Designation phase. During the designation phase, the goal of analysis is to identify dimensions-- ideas or themes that are common to a majority of interviews. The question asked by the investigator during this phase of analysis was, "What all is going on here?" (Schatzman, p.309). This phase is similar to the open coding phase of grounded theory (Strauss & Corbin, 1998). Dimensions are identified, classified, labeled, and various attributes are described. A vocabulary is derived to describe the data (Kools et al., 1996; Schatzman, 1991). Dimensions are established by collecting, scrutinizing, and assembling the data into emerging explanatory pathways. When the investigator perceives that major aspects of the phenomenon appear to be reflected in the analysis, a critical mass of dimensions has been obtained (Schatzman, 1991). After the "critical mass" of dimensions has been obtained, the investigator proceeds to the differentiation phase.

It is during this phase that the researcher developed a vocabulary that generated the necessary cognitive work of analysis from the collected data of the semi-structured interviews. No consideration was given to salience or placement on the explanatory matrix at this time. The density of the experience was explored and the complexity of the phenomenon became apparent. Provisional concepts regarding patient/school nurse interactions, environmental issues, and professional expertise were revealed. Grouping of

similar themes produced provisional dimensions and subsequent sub dimensions that helped to categorize and to identify the range of properties. It was understood that not all of the dimensions and sub dimensions that had been identified would be fully explored in this research study.

Differentiation phase. The second phase of dimensional analysis commences after the “critical mass” of dimensions and their descriptive properties have been ascertained (Schatzman, 1991). These essential dimensions provide a beginning understanding of the phenomenon under study. The next step is the development of a guideline to facilitate comprehension of the phenomenon. An explanatory matrix is constructed to aid the investigator to move beyond a description of the phenomenon to an explanation (Kools et al., 1996). The explanatory matrix represents the cornerstone of the analytic process and “further differentiated the innate characteristics of the identified dimensions into various conceptual components such as context, conditions, process (actions/interactions), or consequences” (p. 318). An explanation of these classifications of dimensions includes the following:

- (1) Context refers to situations or environment in which the dimensions of the phenomenon are embedded.
- (2) Conditions are dimensions that affect the actions and conditions of the phenomenon. Conditional dimensions facilitate, block, or shape the processes involved with the phenomenon under study.
- (3) Processes are the intended or unintended actions or interactions that develop from the conditions.

- (4) Consequences describe the outcomes of the actions and interactions involved with the phenomenon.

It is during this differentiation phase that the investigator identifies the central perspective that depicts the most salient dimension of the phenomenon under study. The central perspective denotes the most explicit explanation for the relationship among the other dimensions (Schatzman, 1991). Moreover, it is placed in the center of the explanatory matrix and provides an organizational schema and significant explanation of the phenomenon under consideration.

Integration phase. The last stage of the data analysis is the integration phase. This phase clarifies the phenomenon by integrating or reintegrating various dimensions according to their relationship with the central and organizing perspectives. Patterns and relationships within the dimensions are described and explained. The synthesis of integration confirms that the central perspective and the relationships among all the dimensions truly represent the phenomenon (Schatzman, 1991).

Participant Inclusion Criteria

Registered nurses who were currently employed by a local urban school district in the southwestern United States were recruited. The selection of these nurses was based on three important considerations: (a) geographic accessibility (b) employment in a school district that served medically fragile students, and (c) a job assignment that involved professional responsibility of one or more medically fragile students.

For purposes of this study a medically fragile student was defined as a student enrolled in the specified school district who was trach-dependent and required daily

ongoing care and monitoring by a one-to-one nurse in order to obtain a free and appropriate public education.

By comparing two district lists (one listing all school nurses and another listing school sites with medically fragile students), the investigator was able to compile a list of prospective participants. Because the investigator was specifically concerned with medically fragile students, prospective participants were nurses who were assigned to schools with or enrolling students who required a tracheostomy (trach-dependent) as noted on the district list.

Professional Connectivity and Gaining Entree

The investigator has been employed in a Special Education Department of an urban school district for the past 20 years. Due to numerous assignments and current employment status, the investigator was aware of specific school nurses who were assigned to schools with medically fragile students. Because the investigator was on a first-name acquaintance with all but four of the participants, the circumstance of gaining entree and seeking a volunteer subject to participate was enhanced.

Human Subjects Considerations

Approval for the study was obtained from the University of San Diego Committee on the Protection of Human Subjects (see Appendix A). Study participants were asked to sign an informed consent form prior to their interviews. Participation in the interview was completely voluntary. Each participant was given a copy of the informed consent form and the investigator's signed copy was stored within a locked box separate from other data.

Potential Risks and Ethical Considerations

Potential risks were identified in the study and included: (a) a breach of confidentiality, (b) invasion of privacy for those interviews conducted in nurses' offices, and (c) potential anxiety associated with sharing professional experiences of caring for medically fragile students. All information that could identify the participants was deleted from the interview tapes and transcripts to ensure confidentiality. Code numbers and pseudonyms were utilized instead of names. Any use of quotable information within the text of the research maintained confidentiality of the informant by use of an amalgam of unidentifiable specifics regarding experiences and stories (Kleinman, 1988, p. 89).

Privacy was maintained during the taping sessions at participants' offices by holding all phone calls and turning off pagers. Further, health office personnel were asked to remain outside of the nurse's office and not interrupt the interview process.

Consideration regarding heightened anxiety was addressed by the creation of a peer-related conversation during the consumption of food immediately preceding the interviews. In addition, if the investigator had detected a reluctance to participate or a personal or professional crisis that pertained to a participant, the anticipated interview would have either been postponed or cancelled.

The need for supportive services regarding participant involvement in the study would have been handled on an individualized basis. Employee-related counseling services within the school system or private supportive services represented two possible considerations for assistance. No services were needed immediately or within the first 15 months following the interviews.

Participant Recruitment

The investigator personally contacted prospective participants by telephone to discuss the components of the study. A total of 18 nurses consented to participate and volunteered to meet with the investigator for a one-to-one interview. No participants asked to be paid for their time; thus no monies were exchanged. Participants who were interviewed at eating establishments were given free lunches and others interviewed at the nurses' offices were given a food take-out order at the investigator's expense.

The final sample included 17 women and 1 man. Informed consent was obtained from each participant prior to the interview (see Appendix B). A copy of the signed consent was given to each participant and a copy was retained in a locked container by the investigator.

Description of Participants

Prior the interview, each participant completed the demographic data form of the interview guide (see Appendix C). All 18 participants had baccalaureate degrees; 10 of which were in Nursing (BSN). The other six baccalaureate degrees were in a non-nursing major; two participants had Associate Degrees in Nursing and four had Diplomas in Nursing. Four participants had Masters of Science in Nursing (MSN) degrees, and two had Masters of Science degrees in a non-nursing major.

The numbers of years in practice as a school nurse ranged from 3 to 24 years, with a mean of 12.3 years. The number of years the nurses worked with medically fragile students ranged from 2 to 15 years, with a mean of 9 years experience. (see Appendix D)

Twelve participants were employed directly at school sites with at least one enrolled medically fragile, trach-dependent student. The other six participants worked as

special education itinerant nurses (SEIN) assigned to a specific geographic area within the school district. Each SEIN worked closely with the site-based school nurses. (see Appendix D)

Data Collection

By mutual consent, 10 interviews were conducted immediately following a dining experience. The investigator negotiated a location within the dining establishment that offered maximum privacy and an opportunity to tape-record interviews without excessive ambient noise. This location offered an opportunity to relax and debrief from the immediate work environment prior to conducting the semi-structured interview. The remaining eight interviews occurred, by participants' requests, within their own school offices and involved a minimum of interruptions. Participants selected the interview times at their convenience. Two interviews took place at the beginning of the workday prior to student attendance, and six interviews occurred at the end of the workday following students' departures from the school sites. A higher anxiety level was displayed by both participants and investigator when interviews took place in nurses' offices in contrast to sessions that occurred in the restaurant settings.

A portable tape-recorder, with an attached microphone and 60-minute tapes, was utilized. The investigator requested all participants' permission to attach a microphone to their collar or near their faces. This enabled them to speak with typical voice quality and volume yet enhanced the clarity of the recordings. No interview lasted longer than 60 minutes. This eliminated any distraction of having to change the tape and prevented miscommunication or interruption of the content of the session.

The stated intent of the research study was verbally reiterated at the beginning and end of each interview. All interviews were structured around an interview guide (see Appendix C). Four questions provided the framework for all sessions:

1. Tell me about the kind of medically fragile students you have in your practice?
2. Give me an example of a situation in which things went well in your practice with medically fragile students?
3. Give me an example of a situation in which things did not go well in your practice with medically fragile students?
4. If you could decide, what would the ideal school nursing practice with medically fragile students look like?

The qualitative interviews were conducted on a one-to-one basis. They were audio-taped and notes were taken before, during, and after the interview process. Observational notes included impressions by the investigator pertaining to the environment, physical appearance, and nonverbal cues obtained from the participants. In addition, theoretical notes were composed that contributed meaning to the observations noted (Schatzman & Strauss, 1973). These theoretical notes elucidated the thoughts and feelings experienced by the investigator. Since it is impossible to note all participant biases, it was important to identify the areas of concern and try to hold them in abeyance while interpreting the data. Many times new concepts emerged from such inferences made by the investigator at the time of the interview. In keeping with the grounded theory tradition, notes frequently involved a comparison of findings from each interview (Strauss & Corbin, 1998). To ensure the accuracy of the data, all transcribed interviews

and theoretical memos were recorded in a timely manner. The majority of transcription occurred within 24 hours of all recorded interviews. Data collection and analyses took place simultaneously, thus keeping the emerging theory grounded in the data.

Methodological Rigor

The acceptance of this study and the trustworthiness of data analysis were enhanced by the process of methodological rigor. Lincoln and Guba (1985) identified four factors necessary for a study to be denoted as trustworthy: credibility, transferability, dependability, and confirmability. These criteria served as guidelines to set forth the goal of trustworthiness in this research endeavor.

In a naturalistic inquiry schema, credibility parallels the scientific inquiry concepts of reliability and validity. Utilizing open-ended questions and verifying whether the investigator ascertained characteristic responses of participants helped to implement and establish credibility. Through persistent observation and return contact availability, the investigator was able to differentiate between typical and atypical situations (Guba & Lincoln, 1985).

Transferability, or generalizability to other populations, is somewhat limited when using the qualitative method of inquiry. The contextual findings of the study that pertained to the environment do have limited generalizability. These findings were specific to a public school setting. However, knowledge obtained from the school nurses and the multidimensionality of their professional role can be transferred or generalized to other areas of nursing. Community health nursing offers such an opportunity. In the study, the information contained in the individual interviews provided sufficient data to allow the reader to generalize the findings to his or her specific needs.

Dependability is concerned with traceability and stability; a comparative criterion in quantitative inquiry would be reliability. Recoding of the texts following the concurrent transcriptions offered a comparative opportunity to determine the stability and traceability in the study. In addition, dissertation committee members reviewed selected transcriptions to ascertain the consistency of the investigator's interpretations and provided further evidence of stability.

Confirmability in naturalistic inquiry is similar to objectivity in scientific inquiry. The emphasis within this criterion involves interpretation, objectivity, and neutrality. The assurance of confirmability in this study involved bracketing the investigator's assumptions. Reflexive examination and commentaries provided further assurance that confirmability had been accomplished. An audit trail of the participant interviews, observational notes, and theoretical memos generated written confirmability of the inquiry process. Dissertation committee members contributed interpretive and objective comments that furthered the criterion of neutrality in this study.

The need for methodological rigor is an important component in the credibility of the research study. The maintenance of integrity within the process of naturalistic inquiry was a compulsory component in undertaking this research endeavor.

Chapter IV: Findings

Study findings were based on interviews with 18 school nurses actively employed in an urban school district in the southwestern region of the United States. They reflect perceptions of school nurses regarding their professional role in caring for medically fragile students in the public school environment. The first part of this chapter provides a holistic view of their lived experiences, and the succeeding sections describe the central perspective and supportive dimensions generated from their data.

Overview of the Theory of Connecting for Success

The Theory of Connecting for Success offered an overall description of the complex dynamics involved with the professional school nurse role. This theoretical model represented a holistic view of the lived experiences of the participants and the interactive processes involved in their work with medically fragile students. To further explicate these processes, an explanatory matrix was constructed to illustrate an overarching framework of the grounded theory. The explanatory matrix contained five related dimensions. The first dimension was Adapting the Environment and indicated a contextual dimension. Claiming Authority and “Standing Out There” were the two conditional dimensions. Striking a Balance was the dimension that was indicative of the actions/ processes and Experiencing Success pertained to the consequences dimension (see Figure 1). Each dimension contained various sub-dimensions that provided additional support and linkage to the central perspective. The emergent theory of Connecting for Success represented a combination of all of these entities. A description

Figure 1. Connecting for Success: A theoretical model of role perceptions of school nurses who work with medically fragile students.

of these findings will commence with the central perspective and proceed to the five related dimensions and sub-dimensions.

Promoting Family/Nurse Connections

Promoting Family/Nurse Connections served as the central perspective in the study. The participants perceived their professional role to revolve around this dimension in their work with medically fragile students. In addition, this connection was the “most important element” that provided a positive integration of the school nurse role. Moreover, participants stated the importance of parents and extended family as a vital source of information regarding the care of medically fragile students. A supporting statement from a participant interview included the following:

Of course I rely heavily on the parents. There's nothing like the parent's perspectives. They're the ones that know their child the best and usually have a routine established in the way they care for their child. They have the child almost 24 hours--at night and such. So I really appreciate the parent's involvement and any extended family as well.

Another participant provided comments regarding parental connections and a conformity to their routines. These connections provided opportunities to gain increased information regarding the student and established a linkage of communication with parents.

I had the parents. Thank heavens I had the fortuitous idea to ask the parents to come to school the first day, just to show us how they fed the child; how they lifted the child; how they diapered or changed the child, so we could visually see this together . . . as we watched what these parents showed us, then we set up our protocols and put everything in place.

Participants emphasized the importance in establishing family/nurse connections as soon as it was feasible. This beginning communication among nurse, student, and family was of paramount importance in a successful transition for the student as well as positive integration of the school nurse role. The recognition and utilization of family collaboration was considered a facilitative factor in the successful implementation of the school nurse role and provided a reference point from which the school nurse could individualize his or her professional care for the student. In addition, it allowed the family to remain in contact with their child's caregiver at school and offered a linkage of shared responsibility to which the child could relate.

Care of the medically fragile student involved commitment and assistance from all family members. The catastrophic reality of a life-long chronic illness and health care needs affected not only the student but also his or her immediate and extended family members. One participant stated, "We do so much more than care just for the child. We link parents to health care and assist them in their knowledge deficits." Another nurse expanded the family concept to include caregivers by reporting the inclusion of "grandparents, aunts, uncles, and respite people often contributed to the benefit of the student and provided us with information that helped in caring for these students."

Each participant recognized the interaction among the nurse, parent, and student as an "integral part of their daily practice." Because there was an involved medical history for all students and because their parents had shared in most of that history, school nurses welcomed knowledge regarding the student's past experiences. Many nurses made home visits in anticipation of the medically fragile student's entrance into the public school environment. Details of positioning, activities of daily living routines,

idiosyncratic fears or anxiety-producing situations, and step-by-step details of ordinary care were helpful for the successful integration process of the student from home to school. In addition, parents were encouraged to be a part of the school integration process. Reliance on parental communication was present as the following statement depicts:

When I talked to mom, she said don't listen just to her heart because it will scare you if you listen just to her heart. Just look at her and see how she's doing. Look at the complete child to see how she is doing and then you will get a better picture of my daughter.

Parents were invited to accompany their child and to offer specific recommendations for educational accommodations. Many times school nurses deferred to parental expertise when a medically fragile student appeared to be in distress. Due to their uncharacteristic individualized patterns of communication, parents offered a rational understanding of what their children were attempting to express. The following illustrates this type of situation:

When she first came to us [the school nurses], we had lots of questions and concerns; what they wanted us to do; and how they did things at home. Many times we did not understand why she was crying. We talked to mom and she said if she cries, first thing take the shoes off and then her socks. . . . She doesn't like anything touching her toes. Things like giving us these little tips when the students are uncomfortable would be so very helpful to us.

The establishment of a parental support group by one school nurse offered an exemplar of family collaboration to many other nurses. Parents often displayed evidence

of unresolved grief with respect to their medically fragile child. Thus, the school nurse and educational staff established rapport with parents and recognized an opportunity to support one other. The following excerpt illustrated this situation:

A few years ago, we started a parent support group. It allowed the parents to talk about the grief cycle or whatever was on their minds. We had guest speakers and that was helpful as well. We even held a luncheon and there were lots of tears and sharing that day. I think this was very meaningful for the parents and it certainly was for the entire school staff.

School nurses and parents often were connected via an extensive trail of paperwork required for school admission of the medically fragile student. Physician signatures, specific medical instructions, and notification of emergency contacts needed to be completed by the parent prior to a child's school entry. School nurses expressed tremendous feelings of admiration and gratitude when family collaboration was evident. One nurse stated:

I know in working with these families and seeing how courageous they are really inspires me to continue doing what I am doing. They appreciate us and understand we are trying to help care for their child. Whether it's little things like a phone call or referring them to a service, their connectivity is enriching and rewarding to our jobs.

Within the school environment, contact with the home represented a beginning source of information regarding the condition of the student. Since many students were unable to communicate verbally, reliance on the parent was important in gaining information and insight into the needs of the child. The inclusion of family collaboration

represented the cornerstone in establishing a successful practice by school nurses.

Participants reported a positive professional experience when parents were cooperative and participated in the student's individualized educational plan. In addition, participants reported negative professional experiences when family collaboration was strained or nonexistent.

The emergence of a negative situation was highlighted when the participants were confronted with the physical presence of the one-on-one agency nurse in the school environment with the medically fragile student yet communication needed to be given to the parent who was not on the school campus. Recently, the district in which the study took place adopted the policy that any student who was deemed trach-dependent by his or her physician would have a one-on-one private agency nurse in constant attendance on the public school campus. The aegis of this directive originated in the school district's legal department and had been in existence since students were first admitted. Its intent was to ensure students' health and safety while on school property. It also produced areas of communication difficulties. For example, participants verified a heightened awareness of responsibility and the existence of boundary issues with parents and one-on-one agency nurses as follows:

I think it is real important that when we work with these teachers and these [one-on-one] nurses, we talk directly to the parent instead of the one-on-one nurse who might be very convenient but really isn't the parent; and shouldn't be the parent. It's a real temptation to talk to the one-on-one nurse who is readily present and available and yet not the parent. I think that needs to be constantly brought to our

attention because the parent needs to continue to feel that they are the decision-makers and are a very important part of the child's educational process.

Other participants offered the following snippets from their interviews:

"The one-on-one nurse was taking it upon herself to make judgments and overtaking the parental role."

"We are not the first hand people...we should not be overstepping boundaries."

"Who are we to be sitting down and telling the parent what they can do with their child?"

"The private nurse appears to be totally enmeshed with the student's needs."

The role of the school nurse who works with medically fragile students was facilitated when boundary issues were communicated within the family/nurse connection. Families needed to be aware of the vast responsibilities incurred by the participants and the manner in which a successful educational process could occur. The participants also needed to recognize when their own boundaries were over-extended. Tenuous situations regarding school nurse versus parental role dynamics were mentioned more than once.

These excerpts serve as an example:

We finally got the company to donate a suction machine to the family. When this happened, it was via one of the community agencies. Since they were considered a vendor, they were the ones that needed to instruct the family. It was so frustrating for me because I wanted to show the parents how to use the suction machine at their home. I had to legally step back and allow the vendor the opportunity to do the home visit, lest I exceed my professional boundaries. It is so important that the parent recognizes that they are the parent, the teacher is the

teacher, and the school nurse is the school nurse. We need to keep these roles clear and the communication strong.

One nurse provided a succinct summation of professional boundary issues by stating that “there is a limit as to what is our responsibility and what is the family’s responsibility . . . and I think the school has taken on a lot.” Providing nursing care for medically fragile students represented a most complex phenomenon. Positive role integration began and ended with Promoting Family/ Nurse Connections, family collaboration, and setting boundaries.

In addition to the central perspective, there were five dimensions that represented the relationships of varying contexts, conditions, actions/processes, and consequences involved with this phenomenon. Attention will now be directed to a presentation of each of these dimensions and the sub-dimensions contained within the specific domain.

Adapting the Environment

The first contextual dimension in which the integration of the professional school nurse role occurred was labeled Adapting the Environment and illuminated the actual surroundings in which the school nurse role was implemented. The public school classroom is a unique environment in which nurse practices represented a significant change from a hospital intensive-care setting. In addition, it offered continual challenges regarding space and accommodations to meet the health care needs of the medically fragile students. Significant adaptations needed to occur because most medically fragile students remained in wheelchairs and required various adaptive equipment and specialized devices for mobility. Most students were unable to walk or climb stairs and were compelled to use ramps and other architectural modifications to enter and access the

public school campus environment. The following quote served to substantiate such realities:

Accessibility had not been considered. There was only one door that you could enter and a wheelchair could never get through it. In addition there were only two plugs in the room and these kids have all these suction machines, fans, VCRs, refrigerators, blenders . . . two plugs in that room! There was no accessibility to the playground. There were 25 steps leading down to that area. Ramps had to be ordered and it took over a year to put them in at that school site. In my opinion it would have been a better choice to place the program at a different site.

Unfortunately my opinion was rarely asked. It seemed we were never asked for our input, but they always wanted us to solve the problems. And it took over a year to help solve some of the problems.

Another reality that surfaced was that students were attending schools that had never been intended to serve such involved students. The following comments offered insight into the expansion of the school nurse role and how Adapting the Environment is very important:

People are more aware of the medically fragile student and their needs simply because we now have them in our classrooms. No longer are they just put in a school by themselves. The medically fragile kids now come to their neighborhood schools with the regular school population . . . they have that legal right and so because of that, we need to make accommodations and focus on these students. Sometimes it takes a long time for accommodations to take place for these students. They need bathrooms, changing space, lifting space, and all kinds of

equipment that are not too different than you would have had in a hospital setting . . . perhaps similar to a minimum care wing on pediatrics.

The dimension of Adapting the Environment contained three sub-dimensions that are designated as classroom setting, cultural sensitivity, and community interface. Each will be discussed in detail and provide additional explanations of context in which the professional school nurse role was involved.

Classroom setting. The care of a medically fragile student was often centered in the classroom setting. Issues that were pertinent to the health and safety of a medically fragile student provided an impetus for the utilization of the school nurse's professional input. Electricity and physical space within the classroom were important considerations.

Since the study is related to the role of the school nurse involved with trach-dependent medically fragile students, the need for electrical sources of power to their G-tube feeding pumps, tracheal suctioning machines, and other specific equipment was a critical reality. In addition, provisions for alternative sources of power likewise rose to top priority for the student's safety. The existence of "rolling electrical black-outs" within the entire school environment meant an emergent situation could result if one battery source was exhausted. The participants acknowledged this alarming reality and provided the following commentary:

For the most part, the one-on-one personnel [assigned to the medically fragile student] that are in the classrooms are excellent. The one little girl with a trach is new to us this spring. . . . When we had the energy shutdown, I realized that we needed to look at the child and make sure we would have enough battery power. If we lose energy in the classroom and on the bus, we needed to have enough

back-up power for longer periods of time. And so working together with this person, we accomplished procuring enough back-up battery power.

Many participants noted an overall lack of space in the classrooms. The presence of wheelchairs, walkers, prone standards, adaptive physical equipment, and various pole standards for tube feedings required an inordinate amount of physical space for each student. During the interviews, participants were asked to comment on their ideal setting for the classroom environment and contributed the following:

The ideal setting for these students would look like a regional center. It would not have architectural barriers or other obstacles that make it difficult for the medically fragile kids to navigate around their school surroundings. It would include space for physical therapists, occupational therapists, respiratory therapists, oxygen equipment, and other specialized equipment. It would be considered a center for enrichment and not a dumping ground kind of place. It could even be located on a comprehensive site and not need to be a stand-alone entity. Most of all, it would contain people who want to be there and who want to work with very special children.

Other environmental classroom concerns that affected the school nurse's role involved electronic communications. Reliance on immediate and reciprocal communication with the parent and health care provider facilitated a positive school nurse experience. For students who experienced unstable physical conditions relating to seizures and requiring frequent changes in their medications, the use of faxes and e-mails within the classroom setting facilitated immediate answers to urgent questions. One nurse stated that her job had become more tolerable since she could "fax a request for a

prescription change directly to the physician and within a matter of minutes, a response could be obtained.” Current status reports regarding a child’s condition were critical to the successful inclusion in the classroom setting. This certainly represented a change from prior circumstances in which students would be required to “remain at home until their condition stabilized.”

Another relevant issue regarding the classroom setting pertained to computer-generated information that school nurses and teachers had regarding students. When a recent 911 situation necessitated the assistance of paramedics, the computerized nurse’s notes and emergency care plan were printed and sent in the ambulance with the student. Inasmuch as the child was non-verbal, computer technology provided the baseline data for the student’s temperatures, respirations, and pulse rates. This information was readily available and utilized as part of the paramedic’s assessment. The nurse was quoted as saying, “We learned that when the paramedics came, that kind of information was very helpful and provided them instant information that they would have found difficult to obtain.”

Classroom technology afforded the school nurses a 24-hour access to physicians or other health care providers in sending or receiving messages regarding the medically fragile student. Reciprocity of communication now existed that provided updated information regarding the student and enhanced the school nurse role. Linkages to various community agencies regarding wheelchair equipment, durable medical supplies, and specific changes in medical appointment times and locations afforded updated information regarding specific students to their school nurse. This facilitated continuity of care needed by students and provided a positive nurse role experience for participants.

Cultural sensitivity. In addition to the classroom setting and physical attributes of Adapting the Environment, participants were cognizant of the importance of recognizing cultural differences. The sub-dimension of cultural sensitivity reflected such awareness. Cultural sensitivity was extended beyond the immediate classroom and encompassed the entire school environment. Because cultural sensitivity involved students and staff, it definitely affected the school nurse's role as perceived by participants in the study.

Within public education today, great efforts are exerted to recognize the primary language and respect the cultural heritage of all individuals. There are relatively few places where this is more vital and important than with medically fragile students. Their tenuous health and fragile physical condition render compliance with medical regimes an absolute necessity. In many interviews, exasperated school nurses expressed "I don't speak their language" or "I'm not a member of their culture." This was particularly apparent when they attempted to answer the interview question describing a challenging school nurse role experience. Fourteen of the interviews contained an expressed frustration similar to the following:

He's getting worse every day. He has lots of respiratory distress; has seizures back-to-back; his mother is Spanish-speaking, and continues to keep sending him to school when he actually should be kept at home... It's hard to communicate with this mom; she cares and loves her son; but I think she is totally overwhelmed.

One subject mentioned her assets regarding cultural sensitivity:

I would have to say that at this particular site, my role as a school nurse is very involved. I deal with medically fragile students that come from many different

cultures and since I happen to be a Spanish speaker, I think I interact well with them. I think my role extends itself because of the fact that I do speak with them directly in their native language and that brings me closer or gives me a deeper insight into their different concerns that they have for their children and also to the dedication that they have to their children.

This research indicated the importance of a culturally sensitive environment.

Information from parents regarding students' medical diagnoses and treatments shed cultural insight into family values, beliefs, and past experiences. In addition, personal definitions and significant meanings attached to cultural and religious traditions provided essential insight to school nurses. Financial priorities, native languages, and interpretations of treatment modalities were helpful in assessing the health care needs of medically fragile children. Additional personal information regarding siblings and/or extended family members was crucial in providing culturally sensitive nursing care to children who were attending school.

From the above quotations, one can appreciate the importance that cultural sensitivity represented to the nurses. Communication barriers and cultural misunderstandings affected the daily challenges faced by the participants. An awareness of deeper meanings and feelings associated with students from different cultures was a critical component in connecting with these individuals and, in particular, with their families. Communication was difficult when not understood; anxiety increased when the health of a fragile student was at stake; and school nurses became frustrated and experienced stress when a lack of cultural sensitivity occurred in their professional roles.

Community interface. The adaptation of the environment, as described by participants, extended beyond the parameters of the public school and included the larger environment of the community. Many participants within this research study referred to the importance of community interface. The medically fragile population involved numerous health care providers and community-based organizations due to students' multiple medical diagnoses. Thus, it was important for the school nurses to maintain professional contact with the community agencies and providers. In some cases, the school nurse accompanied the parent to a physician's office to gain first-hand knowledge of medical circumstances involved with the medically fragile student. One participant offered the following comments:

You can go to the physician's appointment with the child and the parent. You may be able to help the physician to understand how this child is outside of the hospital setting and to present the things that we have to be concerned about in the school setting. . . . Sometimes I find that health providers don't quite understand exactly what it is like to get on the school bus, ride nearly an hour to school, and then be subjected to exposures to all sorts of viruses. . . . And so it's a little bit different when you help everyone understand the unique setting and situations we have at the school sites. I think what really went well in this situation were the parental involvement and my ability to reach the physician and engage in good communication with all parties present. It is not easy.

Another participant gave credence to difficulties existent within various community agencies and how this ultimately affected the school nurse's role. The following quotation exemplifies this type of situation:

Actually one of the problems I see with medically fragile children is that their health needs are all separated into various pots of money. The child has to go through various stages of denial from one agency prior to getting services from another agency. Then the process is reversed or the criteria for admission changes. It is so frustrating because time is passing and the child is getting older and still no services have been rendered. It seems to happen throughout this entire state and it is so frustrating. I wish there was one big pot of money and everyone could access it and we could provide services to those children in a much more efficient manner.

A final example that illustrated the impact and importance of community interface was explained in the following excerpt:

She [medically fragile student] had great difficulty getting medications, a wheelchair, and other medical supplies, as well as treatment by a doctor. She had applied to one agency and they declined her, then she had to be refused by a second agency before she could re-apply to the first one. We had to help her get insurance even if it was on an emergency basis. We continued to help her get coverage for all the treatments and therapies she needs. All of these things that seem easy for someone to procure with insurance are extremely difficult to access if you don't have health insurance.

Community interface was an integral part of the daily practice of the participants and represented the means by which medical consultation, therapies, and equipment could be obtained. This interface extended the parameters of the professional school

nurse role beyond the boundaries of the classroom and into the larger community environment.

The aforementioned discussions have centered on the first dimension of Adapting the Environment. Participants in the study provided cogent information pertaining to their role involvement within a classroom as well as community interface. School nurses' perceptions focused on the overall conglomerate of health and safety concerns of medically fragile students. Concerns of accessibility, physical space, and electrical power sources reflected adaptations that significantly influenced the school nurse's daily practice. There was a heightened awareness of cultural issues regarding heritage and language of these students and their families. The reality of the medical complexities in caring for medically fragile students demanded an interface with the larger community environment. Adapting the Environment represented a most dynamic and supportive dimension in promoting the family/school nurse connection.

Claiming Authority

The second dimension was labeled Claiming Authority and offered an explanation and description of the conditions in which participants performed in the school nurse role. It represented professional characteristics perceived by the participants to be important within the context of a school setting. It signified a professional acknowledgment of substantive qualifications necessary to be effective in school nursing experiences. These qualifications included knowledge of the specific student and their customary physical status, their medical diagnoses, and their prescribed specialized health care procedures. Moreover, it was apparent that participants considered their professional input vital to the

health and safety of the medically fragile student. One participant's interview offered the following:

And they're medically fragile in the sense that due to all their health problems and their congenital problems, that in the blink of an eyelash something could go wrong and they can aspirate; they cannot handle their secretions; and there's always the potential right under the surface for a major emergency. . . . You know by your quick actions and professional judgment that you have alleviated a potential disaster. That when you leave, their color looks good; they're breathing better; and you know they're going to be okay when you leave that classroom. The conditions of claiming authority extended to the family dynamics as well. When the parents brought their child to school and demonstrated how they did the G-tube feedings at home, they laid her completely flat on the table at school and the entire feeding in that manner. I was sitting there with the teacher who had already read our procedural instructions and we both knew they were doing it in an incorrect manner. This child did have recurrent pneumonia and so it was a very good teaching opportunity, and I could let the parents know that probably wasn't the best way . . . although, you know, I can't tell them how to do it at home, but at school, we will be doing it this way. That went well. And they were willing to listen to our rationale and things like that.

Another participant reiterated the concept of Claiming Authority with the following statements:

I believe this is one of the instances when you really need to have the nursing judgment there. Had it not been a nurse making the decision [not to overfeed a G-

tube], maybe it had been a specialized educational technician or some other assistant, they would not have questioned it [the procedure] in her situation. I stood very firm and the parents did agree with me.

The dimension of Claiming Authority represented a condition participants acknowledged as part of their daily practices. This condition seemed to be a reflection of their nursing experience combined with an intimate knowledge of medically fragile students and their families. The second dimension of Claiming Authority included three sub-dimensions: professional knowledge, clinical expertise, and team collaboration.

Professional knowledge. The professional knowledge of participants was necessary to comprehend the scope and breadth of their school nurse role. The number and complexity of medical diagnoses that required nursing care interventions increases each school year. Many nurses described a medical history for a student that began with a very complicated and premature birth and frequently involved prolonged hospitalizations following birth. Characteristic diagnoses of these children were: (a) significant respiratory problems, (b) tracheomalacia, (c) cerebral palsy, (d) developmental delays, and (e) difficult problems with feedings. Complex syndromes involving craniosynostosis, midfacial hypoplasia, syndactyly, broad distal phalanx of the thumb and big toe (i.e., APERTS syndrome), coloboma of the eye, heart malformations, atresia of the choanae, retardation of growth or development, genital hypoplasia, and ear anomalies (i.e., CHARGE syndrome) were represented as well. Severe asthmatics, esophageal problems with swallowing, and possibilities of aspiration usually accompanied many diagnoses. In addition, the insertion of a tracheostomy tube often rendered the medically fragile student

unable to speak. In addition to the above difficulties, significant cognitive deficits were usually present. An excerpt from one nurse included the following:

Medical fragility in and by itself represented an ongoing challenge for all of the school nurses involved with the care of these students. Recognition of the health care demands that accompany these diagnoses required a foundation of medical knowledge, a significant level of clinical nursing expertise, and a presence of sound nursing judgment.

Another participant offered the following illustration:

Right now I have a boy that has a one-on-one nurse. He has a very involved diagnosis and has had titanium rib hinges surgically placed. Right now he is very stable. He does have a trach; he is not mature enough to take care for his trach so he has a one-one-one nurse on hand with him at all times. I do monitor them regularly and know what to look for if he should get into trouble.

Another participant stated:

I would also love to have time to make rounds. . . . In my former life I would have two ICU patients and they would not be as demanding as these children. We have some kids that are on a 24-hour feeding pump and that's the first thing we do when they get off the bus. They come into my nursing office and we hook them up to be fed or to be suctioned, because they're not in good shape.

From the above statements, the need for professional knowledge is well substantiated within the data. Participants faced ongoing crises and emergent conditions during the student's entire day at school. Updated professional knowledge regarding

numerous medically fragile conditions was essential to effective care in the professional school nurse roles.

Tension between realistic educational expectations of the students with global development delays and unrealistic educational expectations from their parents negatively influenced the role of the school nurse. Participants were involved with communicating a “moment of truth” and/or a “touch of reality” concerning the medically fragile student’s physical capabilities as well as educational potential. One nurse expressed her situation with the following excerpt:

Although we have free and appropriate education for everyone, that is a continuum. And there are some medically challenged children that should have everything in the world because they are benefiting from it. They will encounter as much success as anybody else. They will gain from a fulfilling and productive educational experience. But then there are others who are a great deal of responsibility on the system. Their goals are not academic in any way at all. Politically I would try to face the issue of drawing that line somewhere between which children should be served at home and which ones should not.

Further, tensions pertaining to unrealistic outcomes with globally involved medically fragile students surfaced in other interviews. Phrases that verified the existence and continuation of such tensions included “your child’s current academic potential,” “the hopeful outcomes,” and “everything is going to turn out okay.” These statements definitely created anxious and stressful situations, and reliance on their professional knowledge was perceived as essential in their school nurse practice.

Clinical expertise. Due to the longevity of employment by many participants, school nurses acknowledged an ongoing strain between past and present expectations regarding their role. The awareness of a paradigm shift from the aforementioned personal hygiene and communicable disease emphasis to now include specialized health care procedures emerged from the data. Clinical expertise involved the responsibility for safe and effective performance of tracheal suctioning, gastric tube feedings, and urinary catheterizations within a school environment. The school district provided procedural guidelines for these specialized health care procedures and the participants complied with these protocols. The expanding dimensions of the school nurse role involved awareness of acute and emergent care needs and astute clinical competence and expertise. Many participants referred to “the way things were when I first started out in school nursing” and “the way things are today with these medically fragile students.” The subjects stated:

We now need to have current intensive care and critical care experience in order to feel comfortable in meeting the responsibilities that face us with these medically fragile students. Not only are the numbers of medically fragile students increasing, but also are the complexities of their medical diagnoses and the care they need.

The school nurse role expansion was accompanied by constant additional stress. The participants noted that in addition to the specialized health care needs of the medically fragile students their job responsibilities included an entire student body that at one location totaled 3,000 students. This reality represented the scary fact that medically fragile students life-sustaining needs constituted an addition to the already innumerable responsibilities of an entire student body. One school nurse summarized this situation

with the following statement: “I sometimes cannot believe the stress that exists with my work and the fact that these kids [medically fragile kids] are always in the back of my mind whenever they are on campus. Times have really changed.”

The clinical competence and on-going stress that involved the possibilities of life and death emergencies with these students verifies the intensity of the paradigm shift and role expansion of the participants. An ongoing professional challenge remained for the actively involved school nurse to stay abreast of current recommended strategies of care and adapt and integrate these concepts within the school environment. The following quotation from one of the interviews verifies this reality:

We’ve had a situation where we’ve had to call 911 and you have to be on your toes. I guess it reminds me of the days in which I used to work in ICU before coming into school nursing. I definitely use those skills a lot. These students certainly keep me abreast and on top of my skills. . . . I checked her respiratory status and her breath sounds were decreasing; her pulse was very weak; and her pupils were dilated. I called 911 and the parent only to find out that they had accidentally overdosed her medications. There was a new caretaker at the home that had given her too much medication yet insisted she be put on the bus and be brought to the school.

The above quotation reflects the challenge of caring for medically fragile students within a school environment. The combination of professional knowledge and clinical expertise were significant components that contributed to meeting their health care needs. These responsibilities were specifically delineated within the school district specialized health care procedures protocols and represented a systems level of organization and

effort. Any frustrations experienced by the participants regarding issues of competence were related to the systems level and not personal. These responsibilities were not born solely by the school nurses. A multi-disciplinary team was needed and provided a holistic approach to meeting the challenge of their health and safety within a school environment. A third and final sub-dimension was entitled team collaboration.

Team collaboration. Within the school environment the daily health care demands of medically fragile students involved the professional expertise of the school nurse. These participants were well aware that numerous health care personnel were involved with these medically fragile students. Particular to the school environment was a perceived need to collaborate “pull together”, and claim authority regarding the implementation of specific treatment regimens. School nurses relied heavily on the concept of team collaboration yet claimed authority and professional responsibility for the child’s health status at the school site. The following excerpt serves as an example of such team collaboration:

At the risk of being too general, a real challenge to my practice would be the absence of a team approach to the care of these students. . . . If we didn’t have the support and backing of all of the consultants and specialists that help with these children and their educational and medical needs . . . I believe the challenge would be almost insurmountable.

Members of the educational team surfaced as key components in the collaborative efforts of the participants. Most school nurses relied on classroom teachers to offer communication and information critical in assessing the student’s health and welfare. Because of the trach-dependent status of medically fragile students, verbal

communication was minimal at best. Teachers who had constant interaction with students provided the most reliable and immediate source of familiarity and knowledge regarding their pupils. The classroom teacher's experience and comfort level with medically fragile students became the "single most important criterion" to predict the successful and positive experience. The relationship the participants had with teachers was "integral and necessary" in order for them to be effective in the professional school nurse role. The following quotations serve to highlight the positive qualities of special education teachers who assisted the school nurses:

She is spry and energetic and just knows everything. Not only does she have a background in special education, but she also knows a lot of medical information. Her expertise is great. She has dealt with medically fragile students in different venues; she has the patience of a saint; and she is very good at teaching and training and patterning kids. She knows what piece of equipment will help affect this behavior; what kind of program will affect this change. This goes from feeding to toileting to walking to whatever it takes.

Another participant mentioned the following positive effect derived from a good teacher:

The teacher just went way above and beyond . . . where he had all these colorful lights and classical music going, and at lunchtime and recess he would open up his classroom to the whole campus and it became a gathering place for students all over the campus. And that was such a positive experience not only for the medically fragile students and the delayed students that were in the classroom, but

it was an opportunity for regular students to interact with them and have a positive experience.

A final supportive excerpt on teacher collaboration involved the following comments:

The teachers are very well trained and because of this, there are days that the nurse may not be as involved with these students. When the teacher perceives that the condition of the student is beyond her expertise, that is when I get a call and go with an assessment and whatever is necessary for that student.

Team collaboration extended to various occupational and physical therapists as well as speech therapists. These individuals would offer their professional expertise when team conferences were held and provided a complete view of the child. One participant reported the following information regarding her role experiences:

There is a kind of bantering back and forth as far as professions, I see this, and do you see this? And trying to pull out the expertise [of the other professionals], I don't proclaim to be an expert, and I always like to know the teacher's opinion because they're the ones that see the student 99% of the day at school. And the speech therapists sometimes ask questions about the kind of food the children receive with respect to allergies. They use various food samples with their therapies and so we need to collaborate the information to all team members in order to be successful with the child.

In addition to teachers and specialized therapists, the urban school district in which the study took place employed a pediatrician who served as a consultant. His expertise was deemed to be a supportive asset in the school nurse role. Pertinent comments from participants included the following: "I really appreciate the fact that we

have this doctor” and “how wonderful it is to have someone to call when questions go unanswered from the families or private health care providers.”

Another significant contribution to team collaboration that facilitated the participants’ claim to authority involved administrative support at schools. The process of implementing a successful school nurse practice was entirely dependent and proportional to the degree of support and “backing” obtained from the school site administration (i.e., the principal). Medically fragile students presented a formidable task for both administrators and nurses. It was the responsibility of the site administrator to ensure the implementation of the child’s individualized educational program; it was the responsibility of the school nurse to ensure the child’s health and safety within this process. Collaborative support between these two individuals resulted in a positive school experience for the student. Enters the site administrator, school nurse, and the medically fragile student and witness the result when things went well:

With this child and in this situation I had very good support from the site principal. He pretty much backed me on everything. There were times when I had some very difficult situations. . . . The very student that I would continually send home with G-tube feeding difficulties is now attending the local high school. Can you believe that? Thanks to the support from the administrator, things went well and she is doing fine.

Another nurse commented that her successful practice was totally dependent on the backing and support she received from site administration:

With the new regime, we now come under the vice-principal who is totally responsible for all of health, special education, and medically fragile kids. She

grasps the global picture of what we're dealing with and how we all fit in together, and she has been extremely supportive and that has made all the difference in my job.

A participant consensus regarding administrative support revealed that without it, the position of school nurse would have been untenable. The professional knowledge and expertise of the school nurse were significant contributions that prevailed when health considerations were at stake. School site administrators worked "hand-in-hand" and "backed me up" when decisions involved medically fragile students.

The final component regarding team collaboration and a linkage to Claiming Authority involved a heightened awareness of professional peer support. Participants who were designated Special Education Itinerant Nurses (SEIN) stated that the collaboration and support they derived from each other made their jobs "successful and worthwhile." Their role identities and professional actions were verified and validated by those in a similar professional position. The corroborative dimension of peer review and support facilitated their claim to authority. One contribution that provided evidence of the importance of peer support was the following:

I just wanted to say the positives that I have gained from working with these medically fragile students. I have gained the utmost respect and admiration of my fellow special education school nurses. They continue to support me in so many ways, and for that I am most grateful.

Along with peer support was a reference to the school nurse's organization:

And last but not least, I would say my professional school nurse organization has been most supportive to me. When you communicate with peers all over the state

about special education issues, you find out what they're doing and then they can assist you to solve problems with your own specific cases. I know this collaboration has broadened my perspective on special education and working with medically fragile students.

The data did not reveal specific negative challenges evidenced with team members except the perennial frustrations involved with expenditures of time and numerous cancellations of meetings due to the unavailability of various team members. The greater the number of participants involved with team collaboration the greater expenditures of time and number of possible meeting cancellations.

In summary, Claiming Authority represented a dynamic and salient dimension involved in the conditions in which the school nurse role occurred. It provided awareness that school nurses had attained professional knowledge, developed clinical expertise, and integrated team collaboration. These conditions were essential to implementing a successful and effective school nurse practice that connected with the medically fragile student population and their families.

"Standing Out There"

A third dimension that emerged from the data was entitled "Standing Out There." The following *in vivo* quotation was derived from a participant when asked to describe some conditions she experienced in her professional school nurse role: "I mean when you're out there alone and you have a kid breathing at 80 [respirations] per minute because she's been seizing, you have no place to go. You're standing out there . . . alone." This condition was referred to in the majority of participant interviews and was demonstrated in various situations in their professional practice. In addition, it influenced

the implementation of their professional care-giving role with medically fragile students.

The following excerpt from one interview illustrates this dimension:

The teacher called me to the classroom because a certain student didn't look real good. Soon as I got out there, I took one look at him and he was blue-black lying on the table. I immediately went over to him; assessed him; and started CPR. I had the teacher notify the office and had them call 911. And they kept asking, what's going on? I responded, just tell them CPR is in progress. You could tell immediately that the ventilations and the chest compressions were helping him. I could see the difference in his color. I was very glad to see the arrival of the paramedics. They transported him immediately to the hospital. Even though I did everything I could for him I still felt so alone.

Further, additional sub-dimensions of fear and autonomy were included within the "Standing Out There" designation and further illustrated the complexity of this condition that emerged from the data.

Fear. The first sub-dimension under the dimension of "Standing Out There" was fear, an emergent condition that helped to explain the phenomena as perceived by participants. In the study, the ultimate responsibility for the health and safety of the medically fragile student rested with the school nurse participants. Reliance on agency nurses and other educational staff personnel who were physically present with the student was a mandated reality. To best explain the genesis of these mandates, a reference to the historical perspective of special education and school nursing (presented in Chapter II) is recommended. This existent situation represented a challenge for many participants in the implementation of their school nurse role and reflected a sense of concomitant fear.

Medically fragile students with tracheotomies required a one-one agency nurse to be present at all times. This dictum represented a school district policy with which all school nurses were compliant. Most agency nurses were licensed vocational nurses (LVN) and were employed by three private-duty nursing agencies that signed contracts with the school district. The contracts were in effect for a period not to exceed 12 months and could be reviewed at any time by either party. Agency nurses remained employees of a specific agency, and their responsibilities pertained only to specific nursing needs of a child of whom they were assigned. School nurses acknowledged that some real problems surfaced and involved answers. For example, “Where do we draw the line?” “Who is ultimately responsible?” and “Who is going to make sure everything is ultimately okay?” Further, a participant revealed the following scenario involving her fear:

You had 7 or 8 children in wheelchairs being transported on a bus. Who can pick them up in the beginning [of the day]? Who is going to take them to the bus in the afternoon? And it’s just ALL of this that wasn’t in place when the child started. We had a new nurse assigned there as well. So new nurse, intern teacher, and perplexed administrator. It was on a site, that to me was not a very good choice. I would have chosen another site if I had my choice, but I wasn’t asked. . . . It was a horrendous year for me . . . and for the children.

Participants also elucidated their anxieties and frustrations in their encounters working with medically fragile students. One nurse offered the following commentary:

At times one of the most difficult things about these classrooms with these students is that it is unapproachable. Even for me as a nurse with my medical background when I first got into this line of work, I found working with these

students to be difficult for me to approach them, difficult for me to get close to them, and difficult for me to feel comfortable touching them. I was uncomfortable about the procedures, uncomfortable about what their capabilities were . . . just unfamiliar fears of the unknown.

Various interviews contained reference to an anxiety-producing situation wherein the medically fragile student “scared me to death.” Often this fear accompanied the severity of diagnoses coupled with limited emergency supplies and knowledgeable personnel. One participant mentioned she was always happy to work at her school site since it was located “right across the street from the fire station that housed firemen as well as paramedics.” These statements affirmed the realization that fear was a component of “Standing Out There,” and contributed to some very anxious moments for the participants.

Autonomy. Autonomy was the second property labeled under the dimension of “Standing Out There.” This concept provided an on-going antagonistic reality to the aforementioned concept of fear. “Standing Out There” was tolerable due to the presence of professional autonomy and the ability of these participants to exert intelligent and independent professional decisions. Thus, the reality of working as a school nurse within an educational environment demanded independent decision-making capabilities. One participant acknowledged, “The school has taken on way too much responsibility.”

The mere presence of a trach-dependent medically fragile student on a public school campus required serious attention to health and safety issues. The life-threatening challenge of keeping an airway open and a tracheostomy clear served as a beginning illustration of professional autonomy experienced by one participant:

I had a situation the other day in that the girl's trach became clogged . . . it rarely does . . . so rarely the one-on-one nurse had not experienced that. The mom usually removed and cleaned it at home, but it clogged at school. The LVN brought the student into the health office here and she was having difficulty re-inserting it and panic was setting in. I had to intervene.

Another circumstance that described autonomy was the following scenario:

It's not one specific case that stands out in my mind. There are many situations when I'm called to the classroom, when someone is having a tough time and I decide to change their position or drain them or do a little suctioning. I need to intervene right there and then. I need to do something before it turns into an emergency situation.

The perception that this participant acted autonomously, needed to act immediately, and accepted responsibility for these actions was a direct reflection of the conditions that faced many school nurses. "Standing Out There" represented a dynamic condition within the daily practice of the participants. Experiencing fear and functioning autonomously were descriptive sub-dimensions that further explained and highlighted conditions of the professional school nurse role.

Striking a Balance

A fourth dimension that emerged from data analysis involved the processes that participants utilized in their work with medically fragile students. Striking a Balance represented nursing strategies and professional actions that were implemented within the school nurse's daily practice. In addition, this dimension offered three rational underpinnings that supported the integration of the nurse role in working with this

complex group of students. These actions, strategies, and processes were utilized in an attempt to strike a balance between the supply of one nurse and innumerable demands of the total student population. A reflection of this situation is presented in the following excerpt:

With the medically fragile classes, I don't think it's the ideal way it is now, even with the 5 days a week nursing service because that site nurse also has up to 1,200 other kids to serve. So it limits the amount of time she can spend in that special classroom. I feel like medically fragile classroom should have a full-time nurse assigned to the classroom or at least additional nursing personnel . . . to give the extra nursing services the children really need. It's hard to balance all of this into one very busy day.

Further, participants expressed awareness that working with medically fragile students involved a plethora of responsibilities to the "totality of nursing." Knowledge that each day represented new and different challenges was implied in the following comments:

It's been really difficult for me to adjust to this role inasmuch as I spent 21 years in ICU nursing. . . . So to work with trachs, tube feedings, or even dislodged Mickey [G-tube] buttons needing to be reinserted, those types of things don't really try me a great deal. What does stress me is the totality of nursing involved with these kids.

Striking a Balance with regard to adequate health care services for medically fragile children represented a continuum of constant changes and challenges. Balancing the children's health needs and capabilities with their educational rights and privileges was an ongoing part of the school nurse's practice. Some comments by participants were

“being caught in the middle,” “trying to keep a balance between home and school,” and “spending my time negotiating a win-win resolution.” The following quotation illustrates this situation:

I have gotten pressure that we need to get her in school; we need to get her in school right away. And I’m going in my mind that she [the medically fragile student] has never been in school in over 11 years. Why do we need to rush her into the school setting? She has just entered this country and we don’t know her entire health history. She has severe malnourishment; severe kyphosis; and many long-term neglected health problems. . . . I somehow don’t understand the need to do all these things immediately and possibly further upset her entire family.

Within this fourth dimension of Striking a Balance three significant sub-dimensions were identified as assessing medical fragility, prioritizing needs, and utilizing judgment. Discussion of these sub-dimensions provided further elaboration and explanation of their relationship to the professional school nurse role.

Assessing medical fragility. The sub-dimension of assessing medical fragility pertained to the actions and processes performed by school nurses who were involved with the complex diagnoses and physical conditions of medically fragile students. A participant qualifier for this study included responsibility for a trach-dependent medically fragile student. Due to the medical diagnoses attached to these students, potential life-threatening emergencies needed professional anticipation. A review of systems, and performance of emergency protocols specific to the student were performed by the participants. Life-saving measures were required to insure a safe and healthy environment for these students within the public school setting. Participants were queried regarding

various situations in which events went well in their practice with medically fragile students and situations that did not go well. Perceptions of a positive professional school nurse role integration occurred when medical fragility was accurately assessed and emergent care was successfully provided. One participant offered the following scenario:

We had a little boy who was about 4 years old and the teacher said he had been in a seizure for about 2 minutes before calling me to the classroom. I went to the classroom and assessed him. His breathing was fine at that time, but he was having severe clonic-tonic seizures. I brought him immediately to my office and administered oxygen, did vital signs, and assessed him further. We determined that we needed [to call] 911. We notified the parents and he was admitted to the hospital via ambulance.

Upon reflection on the above incident, the nurse further stated:

You definitely see more and more problems with these children. There needs to be someone there to treat them and not let it go without immediate action. . . . More needs to be done; more hours are needed; and there's always more."

Another participant contributed the following medical fragility incident:

We had this little girl who went into a very bad seizure and during the seizure she started vomiting her G-tube feeding. We had to suction her right away so she wouldn't aspirate. It was just a very scary situation, and at last we were able to get control. . . . You really have to think fast and be able to react in a way that's going to be life-saving for that medically fragile child.

The astute assessment of the above medically fragile conditions by the one of the participants was accompanied by additional requests for nursing care and numerous

services for other students at the same school site. The second sub-dimension of prioritizing needs offered enlightenment into this situation and the various dynamics of prioritization.

Prioritizing needs. Prioritizing needs represented various organizational actions and calculative processes the participants performed in working with medically fragile students. Their health and safety issues remained a dynamic and ever-changing complexity. When issues of life and death were at stake, this became a number one priority and immediate action was undertaken. The following comments serve to illustrate this issue:

They call me frequently whenever they have a concern. I run down to the classroom and check out the child. They also keep me informed if the child has had a seizure or if the child's color isn't looking good. There is an instant and almost constant evaluation of these students. There has never been a time that I have not been apprised of a child's situation in the classroom.

Another example of prioritizing needs by the participants involved the following:

I think the medically fragile kids that are non-ambulatory, non-speech, non-vision, or combinations thereof are the most difficult. I don't have the opportunity to get to know them individually. I tend to look more at them and what their medical needs are than to know their specific idiosyncrasies and their individual personalities. It's all in there but regretfully, I don't have the opportunity to get to know them as I would like.

Needless to say when the stakes of life and death were incorporated into the severity of the complex medical diagnoses of medically fragile students, everything else

was prioritized to a secondary level. There existed within the prioritization process the need to address educational rights and privileges of the students. School nurses were often the catalyst by which the medical conditions of the child were balanced with the educational rights of a free and appropriate education in a least restrictive environment.

One participant described the school nurse role in the following manner:

When I do a health assessment for a special education student I just don't look at the physical health care needs; education is very much a part of that student's needs as physical health care. I am looking at grades; I'm looking at social issues on campus, in the classroom, and at home. I'm looking at all of that; it's all a part of that student.

Parental, health care provider, teacher, and school administration demands were in constant competition. One participant emphasized the prioritization of needs in the following excerpt:

Although we have free and appropriate education for everyone, that's a continuum. And there are some medically challenged children that should have everything in the world because they are benefiting from it. They will have as much success as anybody else is having--fulfilling and productive results from their education. But then there are others who are a great deal of responsibility on the system. And their goals are not academic in any way at all. Politically I would try to face the issue of drawing that line somewhere between which children should be more appropriately served at home. I don't think they should not be served, but I'm thinking to put a very medically fragile child on a bus; change their environment completely; send them to school for an opportunity to sit in

their same wheelchair in a different environment seems kind of odd . . . regardless if you have unlimited funds or not.

I think as a school district we need to allow that [home education] to be an option for the family. Don't cut them off; give them services in the home: physical therapy, occupational therapy, and educational services from an itinerant teacher.

Prioritizing needs represented a multi-dimensional process for participants. The multiplicity of physical health and educational needs, coupled with legal and parental demands, presented numerous challenges for school nurses in the daily care of medically fragile students.

Utilizing judgment. From life-threatening emergencies to financial funding resources, school nurses were involved in the utilization of sound professional judgment to assure the health and safety of medically fragile students. A direct quotation from a participant's interview made reference of the need for property to be utilized in the care of students:

This particular little child was about 3 years of age and had a CHARGE association diagnosis with a trach, G-tube, and feeding complications. . . . The parents would insist that we push the formula in her, but I would administer the feeding over an hour and not overload her system. I believe this is one of the instances when you really needed to have nursing judgment. . . . Had it not been for a nurse making the decision, someone else might not have questioned the circumstances and ended up overloading her cardiac status. Nursing judgment was most important.

Professional judgment emerged from interviews with respect to less intense situations. Participants relied on professional knowledge and nursing judgment to assess “the overall appearance and unusual reactions” of the students. Concerns were often generalized and appeared to be somewhat nebulous. An example of quoted excerpts included: “something is just different about him,” “poor color and unusual look,” and “nothing we do seems to make him happy.”

Utilization of nursing judgment became an important determinant for issues of the student’s health status while at school. Because of a constant flux in a student’s physical conditions, nursing judgment was involved to assess and determine whether the medically fragile student remained at school or returned to home. Striking a balance involved professional judgment in reaching these types of decisions. Education of the child was important; balancing their health status with nursing judgment became of critical importance to a successful school experience. An example of school nursing judgment included the following:

He’s getting worse everyday. He has lots of respiratory distress; has seizures back to back; and mother is Spanish-speaking and continues to keep sending him to school when he actually should be kept at home. . . . Mom wants him here and I have to continually tell her he cannot be at school in that condition.

Striking a Balance represented the actions, strategies, and processes used by participants in their daily practice. Assessing medical fragility was built on the foundations of professional knowledge and clinical expertise. Specific actions needed to ensure a healthy and safe classroom for medically fragile students became the responsibility of the participants. In addition, prioritizing needs and utilizing judgment

represented the various strategies and processes involved in the performance of school nurses in their daily practice with these students.

Experiencing Success

The final dimension derived during data analysis was Experiencing Success, which represented positive outcomes or events that resulted from school nurses working with medically fragile students. Participants reiterated the rewards and challenges of their role and most described a positive aspect to their professional experiences. The recognition that the participants' perceptions were distinctively correlated with the students' outcomes was a unique circumstance of this study. For the most part, positive role perceptions emanated from successful school experiences; negative role perceptions resulted when challenges persisted with the student's school experience. Examples of both will be given. Quotations from one interview indicated a positive school nurse experience that involved professional rewards and student's success:

I think that's the one reason why I'm able to do this job because I have this empathy. I really care. And I'm really close to the kids. We literally start to bond with the students and it's so very worthwhile to then see them survive with all their medical problems and be happy and smile. You literally go out of your way to do for this child, to make them comfortable.

Another participant who expressed a less favorable consequence of their school nurse role attributed it to their job placement. Cogent comments from the interview included the following:

Well, basically this has been my first year with medically fragile. And I have to say I was very nervous about taking a school where there were medically fragile

students because I wasn't real comfortable. I was a little hyper-vigilant at first, especially not knowing the child with the trach. I personally would prefer to have a school without medically fragile students.

Three sub-dimensions were contained within the dimension of Experiencing Success: "respecting their gifts," student transitioning, and nurse role integration. These sub-dimensions offered further explanations of the findings that emerged in the discovery process of the school nurse's perceptions of their role with medically fragile students.

"Respecting their gifts". An intrinsic consequence derived from the participants was the *in vivo* category of "respecting their gifts." This phrase pertained to the awareness that most school nurses considered their professional role enhanced by caring for medically fragile students. The "gifts" supplied a meaning and a purpose in the school nurse role and carried the participants through their daily practice. The "gifts" provided the impetus to "go to work tomorrow and look forward to it." One *in vivo* statement that verified these reflections was as follows: "That I can make that child comfortable and happy is what is rewarding for me." Another interview offered the following introspective picture:

I just wanted to say the positives that I have gained from working with these medically fragile students. These are the students who have given me so very much. Their inner strength, their daily determination, their unconditional love, and most of all their sense of humor.

"Respecting their gifts" represented a compilation of intrinsic values participants expressed as a consequence of their work with medically fragile students. They perceived that the students provided a benefit, an enhancement, and a positive contribution to their

daily practice. For example, one participant referred to the medically fragile students she cared for as “being courageous, inspirational, and a true gift” that motivated her to continue working with them and advocating for them.

From intrinsic values received from the students in “respecting their gifts,” participants offered further descriptions of resultant consequences that occurred when there was successful student transition. Discussion of this second sub-dimension will be presented and offered additional information regarding this phenomenon.

Student transition. The culmination of participants’ efforts was reflected in the consequence of student transition. Participants viewed themselves as being successful when students were successful. The monumental home-to-school transition process was extremely tenuous and challenging to the student. Due to the inordinate investment of time and energy, participants viewed their roles as mirroring the success of the student. Most participants grew to know their medically fragile students extremely well and became professionally vested in the transitioning successes. The perceived rewards of this situation were represented in the following interview excerpts:

She had a trach; she had a G-tube . . . and many problems with her feedings based on severe cardiac complications. . . . This little girl is now at a local high school. She surprised us all; she scared me to death. . . . Well I did listen to her heart, but I also looked at the complete child to see how she was doing and I’m surprised that she thrived. Surprised that she has survived so long. Apparently she stabilized and is now on a high school campus. So maybe that was a little positive experience, because I didn’t think that she would have lived that long and I’m impressed that she’s done that well.

Another participant described a similar example of student success:

I love all of my kids. They are just darling and they have grown so much. That's probably the highlight when I see how much they have grown and watch them move on to other programs. And to see them graduate; they'll put on a cap and gown and I actually see them be pushed across the stage. It really is a wonderful experience for all of us.

The following final quote from one participant best reflected the perceived success of student transitioning: "It's been a long road and I know it's going to continue. We have indeed come a long way, and there stands much ahead for all of us in the future."

Nurse role integration. A generation ago, school nurses emphasized health screening, communicable disease control, and health education. Today's school nurse must now combine these foci with updated clinical skills involving intensive care protocols and specialized health care procedures in caring for medically fragile students. As the medically fragile student population increased and complexities of their medical diagnoses grew, the integration of the role of the school nurse changed. One participant stated, "We now need to have current intensive care and critical care experience in order to feel comfortable meeting the responsibilities that face us with these medically fragile students." Another school nurse added, "Things we're doing now in schools used to occur in hospital intensive care units." Another participant verified the need for integration of the school nurse role by stating: "Years ago these children were not allowed to come to school. They were placed in special schools. Now they're coming to school and we need to have a nurse there every day to ensure their health needs are being met."

The role of school nurses working with medically fragile students has evolved into an intricate maze of responsibility, duties, and professional qualifications.

Participants willingly admitted the investment of their energies was rewarded when “respecting their gifts” and students’ successful transitioning lead to the integration of a new school nurse role.

Connecting for Success signified a dynamic process in which the perception of nurse role integration was explained and described in relationship to the medically fragile student population. This emergent theory embodied a dynamic process that pertained to special circumstances in a school environment. Although the genesis of this theoretical model occurred in the professional domain of nursing, it has significance and application to the professions of education, social work, and law.

Chapter V: Discussion of Findings

The purpose of the study was to explore school nurses' perceptions about their professional role with medically fragile students. Based on the concepts of role theory, through the analytic model of symbolic interactionism, the study was concerned with the embeddedness of persons in their social context and the professional role identity process.

The concepts of symbolic interaction originated with the early works of George Herbert Mead at the University of Chicago. Symbolic interaction research and knowledge grew phenomenally in the era between the 1920s and 1940s, primarily in the sociology arena. Because of its prominence, this research became known as the "Chicago School" and represented qualitative and descriptive work (Hardy & Hardy, 1988). The relevance of symbolic interaction in health care rests with the similarities of the theory's concepts and basic assumptions to those found in nursing. The dyad is the focus of study in symbolic interaction, along with the social situation domain in which it is located. The meanings of events and the integrity, or inseparability, of the person and the environment, have been part of the orientation in nursing. In this study, findings were indicative of a focus on school nurse participants in reciprocal social interaction who actively constructed and created their environment through a process of self-reflexive interaction. Social processes and outcomes emerged as they interacted, shaped, and adapted to the public school environment. Numerous concepts involved with role identity, role ambiguity, and role stress were experienced by the participants. The formation of role

identity remained a complex process for these school nurses, a product of self-conception, and the perspective of generalized others. Charmaz (1999) believed that the self as object takes into account sociological notions of the self-concept and is inherently evaluational. Lum (1988) discussed the life-long socialization processes through which persons assume professional roles and attain professional self-identity. It became apparent that some of the participants were experiencing a life-long socialization process as they evaluated their new role identities in relationship to medically fragile students.

Role ambiguity and role strain emerged within the participants as they encountered demands from educational and nursing settings. Similar results were cited in a study by Zimmerman, Wagoner, & Kelly (1997). The duality of educational and health care responsibilities produced a role tension that was inherent in school nurse practices. Striking a balance and prioritizing between the student's educational goals and medical needs exemplified role strain in the participants. In addition, the stress of multiple roles regarding women could also be related to the majority of the participants.

Spurlock(1996) found that the multiplicity and overlapping of roles often provoked conflict and stress. The current study showed indications of such role stress within the aforementioned dimensions and sub-dimensions. Descriptions of such role stress included the architectural problems of space and physical access related to classroom settings; difficulties with technological access to community health care providers; and the on-going frustrations involved with bus transportation for these medically fragile students. Trying to be all things to all people at all times and for the majority of participants, being a woman, contributed role stress and strain.

The concept of role transition from acute settings to school nurse settings was evidenced in some of the participants. Salmon(1994) and Yates (1994) presented supportive findings that with overall health care reforms an expansion of the school nurse role was an expected outcome. The integration of school nursing practice with new models of health service delivery was an important concept the participants described in the study. Community interface signified an expanded role for the participants. School nurses facilitated the implementation of specific health instructions and specifications from the child's primary health care provider to the medically fragile student at the school site. The same process pertained to certain family routines of care and idiosyncratic characteristics of specific students.

The preceding presentations regarding role theory, role ambiguity, role stress, and role expansion serve as a starting point for the discussion of the findings of the study. The remainder of this chapter will focus on the grounded Theory of Connecting for Success and the supportive dimensions that represent the experiences of the participants.

The Grounded Theory of Connecting for Success

Connecting for Success signified a sophisticated dynamic process that encompassed the role perceptions and professional experiences of school nurses working with medically fragile students. Specifically, it represented the integration of the role perceptions within the school environment and the various strategies and processes involved with their resultant consequences. In addition, it included a central perspective of promoting family/nurse connection and contained five supportive dimensions: adapting the environment, claiming authority, standing out there, striking a balance, and experiencing success.

The study was rooted in a recent legal decision of the United States Supreme Court, rendered March 3, 1999, that reverberated throughout the public school systems. The court's decision indicated that Local Educational Agencies (LEAs) would be held responsible for providing necessary medical personnel to assist a medically fragile student to attend a public school to meet the goals and objectives set forth within the student's Individualized Educational Program (IEP) (Greenhouse, 1999). Prior to this time, it had been highly debated what agency would assume the cost of such personnel (i.e., the family, health insurance, or public school district) (Barkoff, 1998). The legal ramifications of this decision had a profound effect on the profession of nursing; in particular, the professional role of the credentialed school nurse (Myers, 1998).

In a seminal publication by the Committee on Children with Disabilities (2001) of the American Academy of Pediatrics, an important distinction was made between medically necessary versus educationally needed services. Health care professionals viewed students from a medical viewpoint and not through an educational lens. Although this was acceptable in the health care setting, it was not the standard for services provided by public school systems. The key component in the law was the additional proviso that services must be necessary for education or special education. Providing related services presented significant opportunities for the children served, yet challenged the educational system--particularly school nurses.

Newcomer and Zirkel (1999) discovered 414 published court cases since 1975 that involved special education conflicts. Thomas and Hawke (1999) discussed the lack of existing protocols and procedures regarding health care services within educational settings. In addition, a proliferation of literature stated conflict reigned and

misinterpretation of federal statutes and regulations continued to exist (Council for Exceptional Children, 1997; Gross, 1998; LRP, 1998).

Given the amount of legal turmoil, this study undertook the goal to explore the sphere of the school nurse who is responsible for the health and safety of medically fragile students in a school environment. In order to ensure a free and appropriate public education for each student, school nurses encounter additional responsibilities. Paramount to the success of this endeavor was the challenge to promote a positive and effective connection with the student's family.

The substantive theory of Connecting for Success focused on the continuous interaction between the school nurse and the work environment. This represented a new dimension within school nursing that involved the care of medically fragile students and contextual considerations, strategies and actions, and resultant consequences that affect the professional role of the school nurse.

Promoting Family/Nurse Connections

The central perspective of Promoting Family/Nurse Connections represented the most salient linkage in the theoretical framework and served as an important concept that emerged from the interviews. The family/nurse connection proved to be the synergistic conduit for all that was occurring within the school nurse/medically fragile child world. Byrd (1998) investigated the relationships that evolved between families with children with special needs and public health nurses. Characteristics of trust, support, familiarity, admiration, reassurance, and validation were considered significant in effective care of the child. School nurses stated these same attributes were important components in their connection with the families of medically fragile students. Trust, support, familiarity,

and reassurance surfaced with respect to routines of care; admiration and validation were present when established specialized health procedures occurred at school in a safe manner.

Webb, Tittle, and VanCott, (2000) studied families of children with developmental disabilities. The researchers' goal was to facilitate sensitivity to and understanding of the child's needs. The children posed a challenge to nurses and health professionals because each individual and his or her family represented a unique combination of intellectual, emotional, and medical concerns. The child's disability was diagnosed during infancy or early childhood and was expected to last a lifetime. Respect for the family support system and a validation of their expertise was needed from health professionals (Faux & Seideman, 1997). Parents indicated they wanted to interact with professionals who were committed to developing open, honest, and collaborative relationships. Similar findings occurred in this research study. Parental input was actively pursued by a majority of participants, especially when the child first entered the school program. A concerted effort to work together and promote a mutual trusting connection with the family emerged from the interviews. Further, parental involvement and connection to activities of school nursing were deemed "integral parts of my role."

During the past decade, children with special needs and those who are technology-dependent were able to leave the hospital and received care at home and in daycare centers (Delaney & Zolondick, 1991; Fleming, Challela, & Eland, 1994; Patterson et al., 1992). The dynamics of the parent-professional relationship surrounding the child's health care were vitally important in the successful transition into the community environment. Factors that contributed to a positive parent-professional

relationship were professional competence, genuine caring for the child, and respectful and supportive collaboration with the family.

This study supported the above findings. Positive parent-professional connections, genuine caring for the child, and collaboration efforts with the families of medically fragile students contributed to a successful school experience as perceived by the participants. The admission of medically fragile students to a public school campus served to magnify the existent potential for life-threatening emergencies. Each participant in the study was responsible for the health and safety of these trach-dependent students. This situation contributed additional professional responsibilities to the school nurse and verified the need to have a respectful and supportive collaboration with the family.

Promoting Family/Nurse Connections specifically entailed the process of family collaboration, and all participants in the study stated the importance of “including the family.” These findings supported the competencies set forth in a family care-giving model that was developed by Zerwekh (1991). Without question, the know-how of parents was critical to a successful transitioning of the medically fragile student from home to the school setting. Parental recommendations were an excellent source of information and their input in the school setting created a sense of empowerment and mutual respect (Hulme, 1999).

Ford and Turner (2001) described special relationships that developed between pediatric nurses and hospitalized children with special needs and their families. Due to the chronicity of certain illnesses, parents were intimately involved with their child’s health care. Within a relatively short period of time, health care personnel expressed positive attitudes towards parental participation in their child’s health care routines

(Claassen, 2000; Kearney & Griffin, 2001). These findings correlated to the results obtained in this study. The intense daily involvement of parents regarding their children's health care concerns merited the participants' trust and respect. This collaboration with families provided valuable information to the school nurses. Knowledge regarding the idiosyncrasies of the child and familiarity with the daily routine of care at home were especially relevant to a positive nurse role experience.

Parental input and family collaboration concepts created another effect of setting boundaries for the participants. This was particularly relevant to the delineation of responsibilities once the medically fragile student entered the public school arena. Thies (1999) studied the educational implications of chronic illness in school children. Confusing terminology, intersecting health and educational systems, and differing philosophies contributed to role diffusion and boundary intrusion. Moreover, Thorne, Radford, and McCormick (1997) discussed the need for a clear distinction between professional and personal roles of the nurse. Findings indicated that when the patient became "my child," professional boundaries were obscured and difficulties arose for all concerned regarding the health care of the child.

Findings of this study supported an awareness of professional and personal boundaries. Emphasis on communication with the parent was extremely important even though a one-on-one agency nurse was physically present with the child at the school setting. Many experiences were perceived as generally positive and helpful to the student; however, some situations provided for a definite increase in professional nursing responsibilities. Nurses were the party ultimately responsible for the health and safety of the students, and parents remained the primary contact persons. Further, boundaries

issues involved with parents, one-on-one agency nurses, and site school nurses remained a unique finding of the study.

Following the presentation of the central perspective, discussion will now proceed to the five supportive dimensions of the substantive theory: Adapting the Environment, Claiming Authority, “Standing Out There”, Striking a Balance, and Experiencing Success.

Adapting the Environment

The dimension of Adapting the Environment focused on the contextual conditions necessary for school nurses to conduct an effective practice with the medically fragile student population in the school setting. This supportive concept began with the assessment of the immediate environment of the classroom setting, spread to the awareness of cultural sensitivity throughout the school, and expanded into the extended environment of the community.

Most participants stated the need for adequate space and physical access to the classrooms. Since most students were wheelchair-bound and needed a plethora of medical equipment, these were important considerations for school nurses to incorporate within their professional responsibilities.

Included within the adapting environment dimension was a larger perspective of the entire school that focused on the recognition of cultural sensitivity to all students. The importance of transcultural nursing has appeared within nursing literature throughout the last two decades, and Leininger (1977) is credited, more than anyone else, with pioneering cultural concepts in nursing. Recognition of clients’ cultural beliefs, norms,

and values were essential to provide care that was responsive to the recipient's cultural perspective.

Cultural sensitivity referred to the awareness and use of professional knowledge related to ethnicity, culture, gender, or sexual orientation in comprehending the responses of clients and their environments (Baker, 1997). Nurses needed to recognize the importance that illness may have for the individual's identity and purpose in life and to be cognizant of the medically fragile student's past experiences (Richer & Ezer, 2000).

Participants expressed a keen awareness of the importance of cultural sensitivity. Canales and Bowers (2000) presented an expanded conceptualization of culturally competent nursing care in which no distinction is made between competent care and culturally competent care. The emphasis remained to directly connect with those needing care, regardless if they are perceived as different from oneself. This same concept of care existed with medically fragile students who received competent nursing care, regardless of their culture. The "otherness" of their customs, languages, and cultural norms provided additional information to participants. Most recent literature involved with nursing care and cultural sensitivity emphasized the importance of connecting with families, developing an understanding their social, political, and economic circumstances, and creating an awareness of their language and historical labeling (Absalom, Beil, & Schliessmann, 1999; Cohen & Palos 2001; Kavanaugh & Kirkham, 1998; MacAvoy & Lippmann, 2001). Participants in the study experienced a positive working relationship with families when cultural sensitivities were recognized and respected.

A final sub-dimension that was included within the adapting the environment area was community interface. This represented the role responsibilities of the school nurse

who moved beyond the classroom and into the external environment of the larger community. Included in the care of the medically fragile student was a listing of numerous health care professionals, community agencies, and medical equipment services. These primary medical health care providers were connected with these children and provided active and consultant services while the medically fragile student was in school. This circumstance provided further opportunities for participants to promote the collaborative services and maintain professional contact and communication with providers.

Flynn (1997) described the importance of maintaining collaborative services and coordination of providers from a community perspective. Bringing the right people together at the right time enhanced shared responsibility and accountability. Gaffrey and Bergen (1998) presented effective, timely, accessible, and cost-effective services to children when community managed care collaborations were involved. The success of partnerships between school nurses and community health providers may result in improved access to health care, greater attention to preventive services, and an optimal setting for health promotion.

The study's findings corroborated the results of the cited nursing literature. A unique contribution from these participants was the specific environment of a public school settings in which they worked and implemented their professional nursing roles. Discussion has centered on various adaptations to the internal environment of the classroom settings, the school-wide environment involved with cultural sensitivities, and community interface in the external environment.

Claiming Authority

A second dimension perceived by the participants about their professional roles was entitled Claiming Authority. This dimension included the foundational and structural conditions participants needed within the scope of their school nursing practice. Knowledge of the specific medical diagnoses and projected prognoses of these students was important information for the nurse to obtain and comprehend. In addition, clinical expertise obtained from past nursing experiences was adapted to the specific context of the school environment. Team collaboration contributed the final integrative component to this dimension. Support of a paradigm shift of the role of the school nurse became evident within this particular dimension.

Current professional knowledge and updated clinical skills represented requisite qualifications as perceived by the participants. Children with complex medical diagnoses with specific nursing procedures have emerged from the hospital bedside to public school classrooms. This situation has increased school nursing responsibilities and expanded professional school nursing roles. Clinical nurse specialists now practice within schools and other community settings. Ross (1999) explored the expansion of the clinical nurse specialist in school health. The clinician, educator, consultant, researcher, and leader/manager roles provided a comprehensive description of nursing roles implemented with school health services to students, their families, and the community. These same roles were utilized in serving medically fragile students and their families. Participants in the study have offered examples of clinician in their care of these children, of educator when instructing the parents these students, and of leader and manager when offering professional guidance to the one-to-one nurses.

Bowden (2000) recognized the effect that extensive technological and medical advances have had on the way nursing is practiced. Thies (1999) acknowledged the same medical advances that allow adults to live longer have created an emerging population of children and adolescents with chronic health conditions. The numbers within this diverse group of children have increased, and their medical needs continue to pose a distinct challenge to schools. Recognition of the growth in the number of medically fragile students and their complex health care needs substantiate a need for professional knowledge of physical health care procedures within a public school setting. The presence of medically fragile trach-dependent students in public school settings set forth a demand for nursing expertise. This expertise includes proficiency with procedures involving tracheal suctionings, gastric-tube feedings, and urinary catheterizations to name a few. Participant compliance with specific school district recommendations regarding these health care procedures was also maintained.

Clinical expertise was related to the need for professional knowledge among participants. This emanated from recent advances in neonatal and pediatric health care research. An outcome of this research has been the survival of medically fragile students. Multidisciplinary and complex health care needs have produced a complete paradigm shift in the school nurse role. The former emphasis on first aid and communicable disease control has given way to specialized health care procedures and one-on-one nursing assignments.

Bonaiuto (1995) found that school nursing competence was the most critical issue for students who were technology-dependent. Similarly, Igoe (1999) advocated that school nurses be prepared and educated as school nurse practitioners. Advancement in

technology and medical research has made it possible for medically fragile students to survive and attend school. The domain of school nurse responsibilities must include the clinical expertise to care for medically fragile students.

In addition to the attributes of professional knowledge and clinical expertise, participants imparted an awareness of the need for team collaboration, especially when it involved the medically fragile student. Contributions from nursing as well as educational literature supported the concept of collaboration. Within the nursing literature, Chan and Filippone (1998), Heaman (1995), and Weber (1998) supported a well-defined, organized, and multidisciplinary program of health care to become integrated within the special education process. Parette et al. (1994) advocated that a collaborative approach between educators and school nurses be used with medically fragile children to ensure safe and effective services. McClain and Bury (1998) extended the collaborative responsibility to include parents, medical staff, social workers, specialized therapy providers, and all educational personnel involved with the health and welfare of the student while attending school.

When school principals were queried in the Brotherson, Sheriff, Milburn, and Schertz (2001) study, collaboration was the key to making changes. The success of inclusion of special education students relied on collaboration with school personnel as well as community members. Many students involved in this study had numerous professional members on the IEP team. The disciplines of occupational therapy, physical therapy, speech therapy, vision therapy, and professionals involved with vision and hearing deficits were represented. These individuals were in addition to the specified administrator, classroom teacher, school counselor, school psychologist, and school

nurse. Due to the number and diversity of members, team collaboration was an absolute necessity for school nurses to successfully implement safe and effective health care services.

“Standing Out There”

“Standing Out There” represented a dimension of qualitative conditions and descriptive texture of the school nurse’s practice with medically fragile students. The title for this concept represented an *in vivo* code derived from one interview that symbolized the feelings experienced by participants in coping with their daily responsibilities. In addition, it contributed insight into the participant’s professional role and acknowledged feelings of fear, yet being autonomous in the practice setting. From the empirical data of the interviews in which “being scared to death” and “feeling better knowing I am right across the street from the fire station” were described, the reality of fear was distinctly present for the participants. The nursing literature addressed the dynamic of fear in relation to job satisfaction.

Fletcher (2001) conducted a study regarding feelings of distress and dissatisfaction among hospital nurses, and work-related stress involving patient care issues. Large numbers of patients with few nurses to care for them contributed to fear and frustration within the hospital environment. Simmons, Nelson, and Neal (2001) compared positive and negative work attitudes between home health nurses and hospital nurses. Their study suggested that due to numerous changes in the health care industry, nurses become angry and frustrated when they believe events beyond their control might interfere with their ability to deliver quality care to patients. There remained a paucity of

nursing literature with respect to feelings of distress and fear exhibited by school nurses who worked with medically fragile students.

Feelings of autonomy represented another component of “Standing Out There.” Participants stated that being alone or practicing autonomously created both positive and/or negative attitudes. When the participant’s nursing experience was favorable, it reflected a positive perception of autonomy. However, when the nursing experience was negative, autonomy was often questioned within their role integration process. When students’ health status worsened or a crisis occurred within a classroom setting, being autonomous was suspect of a negative reality. The lack of readily available professional help when things were not going well created a circumstance of discomfort and negativity for the participants.

The concept of autonomy was well represented in the nursing literature. Many years ago, Lewis and Batey (1982) defined “autonomy” as the freedom to practice, independence in nursing and decision-making, and the ability to self-govern. Keenan (1999) presented an operational definition of autonomy by stating it involved an exercise of considered and independent judgment to affect a desirable outcome. Wade (1999) provided an updated concept analysis of professional nurse autonomy, describing it as a unique phenomenon that involved affiliated relationships with clients and collegial relationships with others. Discretionary decision-making, a key component of professional nurse autonomy, is based on nursing knowledge and not on emotions or the exercise of routine tasks. Autonomous nurses are accountable for their decisions, feel empowered, and may influence the profession of nursing. Aveyard (2000) supported the idea that clarity of the meaning of autonomy was crucial within professional nursing

practice. Krugman and Preheim (1999) linked professional nursing autonomy to nursing practice redesign, while Roper and Russell (1997) presented the relationship between autonomy and peer review. The concept of professional nursing autonomy in school nursing practice constituted a significant finding in this study. The concept was grounded in the participant interviews and supportive of the *in vivo* dimension of “Standing Out There” within the theoretical framework.

Striking a Balance

The fourth dimension depicted within the explanatory matrix was labeled Striking a Balance and represented a descriptive context of actions, processes, and strategies employed by the participants in their work with medically fragile students. Attainment of striking a balance affected the daily practice of the participants. The give and take between the realistic conditions of medical fragility and idealistic educational goals and objectives remained an ongoing dynamic process throughout the child’s educational program. The maintenance of a functional equilibrium between the health capabilities and educational possibilities of medically fragile students remained an issue of concern and constant challenge for the school nurse participants. They were continually involved with assessing the medical conditions of students, prioritizing their medical and educational needs, and utilizing professional nursing judgment within their daily practices. Assessing medical fragility remained an ongoing daily action and nursing process for the students. Advances in medical sciences, particularly within the specialty of neonatology, have contributed to the improved survival of extremely low birth weight infants. Much of the literature is devoted to the first-year survival rate and transitioning from the hospital to the home (Miles, Holditch-Davis, Burchinal, & Nelson, 1999). It has only been within the

past decade that medically fragile children survived to reach school age. With greater numbers of children with chronic diseases and disabling conditions entering the school system and the increasing complexity of their conditions, many issues and problems have developed. One of the specific difficulties is the uncertainty regarding the responsibility for and administration of complex nursing treatments or prescribed therapies in schools. In this study, it was the school nurse who accepted the primary responsibility of the medically fragile student's health and safety on the school campus. Assessing their medical fragility remained the first action many participants performed when working with the medically fragile students.

The prioritizing needs sub-dimension involved consideration of potential risks and physical limitations. Although all school-aged children are entitled to obtain their education in a school setting, discussion of students' physical tolerance and scheduled medical therapies greatly influenced their educational programs (Taras et al., 2000). For some medically fragile students, entrance into the public classroom offered first-time exposure to other children in the setting (Lynch, Lewis, & Murphy, 1992; Sexon & Madan-Swain, 1993). For example, common upper respiratory viruses and various environmental allergens were part of daily communication to parents and other health care providers. Participants were extremely attentive to the physical conditions of the students and on-going evaluations of risks and limitations occurred. Respected input from parents, written documentation from classroom teachers, and consulting professionals were supportive measures to the prioritizing needs sub-dimension.

The final component of "Striking a Balance" involved the utilization of nursing judgment. Some participants previously worked in intensive care or critical care units of

hospitals and felt their experiences contributed to professional judgment and decision-making capabilities. According to Benner (2000), within nursing practice lies its legacy and one learns to be a practitioner through education and socialization into the practice by other practitioners. The wisdom of nursing practice includes clinical judgment and requires moral agency, relationship, perceptual acuity, skilled know-how, and narrative reasoning in order to promote effective nursing care.

Buller and Butterworth (2001) stated that skilled nursing practice involved the value of embedded knowledge and intuitive clinical judgment. Cox, Wood, Montgomery, and Smith (1991) reported the most sensitive variable predicting outcomes for acutely ill patients in home health settings was professional nursing judgment. Thus, the nursing judgment sub-division has been substantiated within the nursing literature.

There is a lack of any reported findings with respect to school nurses and their nursing judgment in the care of medically fragile students. A combination of assessing medical fragility, prioritizing needs, and utilizing judgment represented the nursing actions, processes, and strategies employed by participants. The dimension of Striking a Balance involved caring for each individual student on a daily basis with a constant concern and never-ending change in their safety at school. This dimension was particularly evident in the thoughts of the participants and represented an inordinate amount of time and energy.

Experiencing Success

The final dimension within the explanatory matrix represented resultant consequences. It was labeled Experiencing Success and reflected varying results that participants encountered when working with medically fragile students. Overall,

participants viewed their efforts as ultimately being worthwhile and satisfactory. These consequences related to positive job satisfaction despite the degree of daily change and challenge they encountered. Fletcher (2001) affirmed the reality that both the work climate and type of duties performed by nurses generally produced a great deal of stress; especially in interpersonal relationships. Paradoxically workload, patient care, interpersonal relationships, nursing knowledge and skills, the type of nursing, and bureaucratic/political constraints can be sources of both stress and satisfaction.

Simmons et al. (2001) compared the positive and negative work attitudes of home health and hospital nurses. The strongest positive attitudes were meaningfulness and hope; conversely, the strongest negative attitudes were attributed to the demands of the job and frustration of the overall system in which the nurses worked. Participants in this study experienced similar positive and negative attitudes.

Three sub-dimensions were included within the dimension of Experiencing Success: “respecting their gifts,” student transition, and nurse role integration. “Respecting their gifts” represented an awareness of intrinsic values attached to caring for medically fragile students and provided an introspective context to school nursing practice. Participants acknowledged an awareness of courage, inner strength, and daily determination exhibited by the students, attributes that became an inspiration and motivation to school nurses. In addition, school nurses contributed to the perpetuation and continuation of professional practice and were afforded an opportunity to grow within their own identity as caring human beings. Moreover, “respecting their gifts” represented the participant’s story of giving good nursing care. Nowhere in the literature was this experience more supported than when Benner (2000) stated: “Nurses must

continue to tell their stories so that the hidden bedrock of caring practices for a healthy and good society will become more apparent to all. Through our stories, the intangible can become tangible, and the artfulness of good nursing practice can be rescued from the margins” (p. 105).

A second sub-dimension of Experiencing Success was student transition.

Participants experienced this consequence as they witnessed the student’s successful transition from the home to school environment. As students became more acclimated and adjusted to their routines of care and daily educational programs, nurses experienced a concomitant feeling of success. Rosenkoetter, Whaley, Hains, and Pierce (2001) described the transition process of young children with special needs and their families. Although directed towards special education, the recognition of various transitions was noteworthy and provided awareness to nurses.

According to Rosenkoetter et al. (2001) early childhood transitions occurred in many families with children who had special needs (i.e., hospital to home, entry into special services, early childhood intervention to preschool, and preschool to kindergarten). Other common transitions included those within hospitals during the neonatal period, a child’s repeated hospitalizations with subsequent re-entry into the community, family moves from place to place or program to program, and introduction to new personnel within an existing program. In this study, the energies and efforts of the participants to provide a successful transitioning from home to school for medically fragile students remained a complicated process. The realization that most of a child’s very young life was spent in constant transition has afforded both the medically fragile student and school nurse an opportunity to experience success and to recognize personal

and professional accomplishments. The same situation applied for the older special needs student who transitioned from school to the community. These students provided participants a vivid recognition of their successful accomplishments when some school nurses were included in high school graduation ceremonies. Sawin et al. (2001) described the need for transition planning in family, health, education, employment, and community systems. Further, Betz (1998) addressed multiple nursing concerns regarding adolescent transitions. The multifaceted and interdisciplinary participation that is required for this process to be successful definitely had strong application to pediatric, school, and community nursing constituents.

Nurse role integration was the final sub-dimension. From the beginning with Lina Rogers in New York City to the current status in the southwestern United States, the role of the school nurse has definitely changed. As one example, the exclusion of sick children and reduction in the spread of contagious diseases has now expanded to include a nurse specialist who cares for medically fragile students. In this light, Oda (1979) advocated for the development of a specialized role for school nurses and referred to the unique interaction that occurred between each care-giver and specific school setting. Igoe (1980, 1999) and Brindis et al. (1998) continued to focus on the concept of a school nurse practitioner to provide care within the actual school setting. In addition, Bonaiuto (1995) supported the role of the school nurse giving care to students who were technology-dependent.

The current study verified significant changes have occurred within the professional role of the modern school nurse specialist as perceived by the participants. The integration of present school nursing roles reflected a culmination of professional

knowledge, clinical expertise, and multidisciplinary collaboration utilized in promoting a family/nurse connection. The *in vivo* contextual dimension of “Standing Out There” represented a most interesting description involving fear and professional autonomy. The resultant consequence of experiencing success was described from the components of “respecting their gifts”, student transition, and effective nurse role integration.

Special education mandates and advances in medical technology have produced a plethora of amazing accomplishments and extraordinary challenges for modern society. The care of medically fragile students is representative of these challenges. School nurses perceive a significant change in the integration of their professional role in caring for the medically fragile students within the school environment. Connecting for Success helps explain the qualitative components involved in this extraordinary dynamic process.

Chapter VI: Implications and Recommendations

The impact of medical science research and the resultant advances within the specialty of neonatology have resulted in the presence of medically fragile students on public school campuses. The prolongation of life in these children indicates the need for inclusion of school nurses in their educational processes. Their numbers and the medical complexities associated with these special children continue to increase. This situation intensifies the challenges of the professional role of the school nurse. Individualized educational programs now incorporate more complex specialized health care procedures. Medically fragile students' access to a free and appropriate public education is now mandated and supported by the "related services" of a school site nurse and/or one-on-one nurse. This study examined changes in the school nurse role attendant on these circumstances and its findings have important implications for nursing practice, nursing education, health policy, and nursing research. This chapter includes a critique of the study and presents implications and recommendations for the future.

Critique of the Study

Research with school nurses who work with medically fragile students is limited. Numerous articles exist regarding the care of chronically ill children, but most concern hospital and home settings and do not address issues involved with schools and school nurses. Because in the past medically fragile students did not survive to reach school-age, there was no established connection with school nurses. The inclusion of special children within the public school system remains an overwhelming challenge, and the inclusion of

medically fragile students presents an even more arduous task. This study provides an explanation of the process of professional role integration for school nurses who work with medically fragile students. It presented a vivid picture of the multi-faceted responsibilities of today's school nurses as they solved numerous dilemmas in the process of simply getting the child to school. These included adaptations to the school environment, access ramps, bus transportation safety issues, maintenance of adequate battery power, and adequate physical space within the classrooms. Numerous descriptions of health-related incidents that occurred within the school environment demanded the utmost professional knowledge and clinical expertise from these participants. Respect and recognition of these students' intrinsic gifts (e.g. sense of humor, smile, and perseverance) and successful student transitions promoted a professional role integration that was perceived as a successful experience.

A critique of the study includes limitations. Information from parents, students, and school administrators is absent from the research endeavor. School administrators were omitted due to their high mobility, numerous job assignments, and difficulties of access. Parents and students were excluded for this study due to the complexities involved with vulnerable populations. These three populations would contribute a wealth of information and knowledge regarding the medically fragile student and shed additional light on the role of the professional nurse.

Other areas of limitations pertained to participants and their demographic variables. Participants in the study were all registered nurses who had a wealth of professional school nursing experience. Many had first-hand knowledge of medically fragile students on a public school campus within the selected urban school district. Their

perceptions of professional role integration represented a historical contribution to school nursing as well as the establishment of baseline data from which nursing adaptations can occur. The demographic data is representative of a preponderance of female and Caucasian school nurses with only one African-American, one Hawaiian, one Hispanic, and one male nurse in the participant group. These findings may be significant limitations regarding ethnicity and gender.

Additional limitations attached to sample size and purposeful selectivity can be attributable to the study. Information from a larger sample of school nurses and from other urban and rural school districts would be recommended for future research.

A final area of limitation involved with qualitative research was the ongoing dilemma regarding personal bias and researcher reflexivity. This investigator is a school nurse and achieved a first-name acquaintance with most participants. The circumstances of gaining entree, clarifications of unclear meanings in the interviews, and perceived mutual respect between researcher and participant may be indications of personal bias. The intrinsic personal motivation to recognize and salute professional school nurses will forever usurp this perceived or real limitation in the study.

Connecting for Success is an emerging theoretical perspective that provided an explanatory model of school nurse role integration specific to medically fragile students. This initial research study should be enhanced and further explored in larger studies with a broader range of participants. The identification of key or sensitizing concepts and dimensions germane to school nursing practice should be incorporated into other specialities of nursing research such as home health, public health, and community nursing arenas. An ongoing recognition of the dynamic complexity of the Connecting for

success grounded theory remains self-evident and gives rise for future verifications and variances to be established. Such information may serve to limit or expand available resources for school nurses and better ensure accessible, comprehensive, continuous, compassionate, culturally competent, and family-connected nursing care for medically fragile students.

Conclusions and Implications

Conclusions and implications regarding health policy, nursing practice, nursing education, and nursing research will be presented. A summary will be included at the end of this chapter.

Health policy. Federal and state mandates, budgetary re-appropriations, and student-school nurse ratios are significant contributions to the legislative agenda. The findings of this study can provide an impetus for reassessment and possible changes in legislated health policy for medically fragile students. The current status regarding medically fragile students who attend public schools remains extremely complicated within a maze of mandates and funding streams. Federal mandates need to be revisited with respect to their overall purpose. From the first inception of Public Law 94-142 in the 1960s, the principle that all children have the right to an education has been at issue. The 40 intervening years of medical research have produced outcomes that far exceeded the intent of the original laws. Current laws, including Americans with Disabilities Act and its revisions have made a valiant effort to address the rights of medically fragile children to education. The inclusion of school nursing expertise could add a dose of reality and true lived experiences to such legal discussions. This study provided an initial grounded awareness of the complexities that are involved in the care of medically fragile students

in public school classrooms. The importance of this knowledge definitely needs to extend beyond nursing and into the thoughts of federal and state lawmakers.

It is a rare legislator who is fully aware of the complexities associated with the public education of medically fragile students. Few politicians are cognizant of health care provisions required to ensure the health and safety of these students on a public school campus, let alone to support their educational needs. Federal mandates regarding special education rights need to create concomitant reapportioned funding specific to this special population.

Current costs for mandated special educational services have exceeded all approximations and significant encroachment has resulted on school districts' general education budgets. When allotments for special education expenditures are exhausted, expenses are often paid from general education budgetary allotments. This trend cannot continue; revisions and changes in health care policies within public schools are imperative. This study presented a beginning awareness of the scope of professional practice performed by school nurses who care for special children. Recommendations for further study to explore the costs and outcomes encountered in the area of special education will provide pertinent knowledge that is needed at both the federal and state governmental funding levels.

Current health policies also affect the concerns of the State Department of Education. Issues regarding medically fragile students are not specific to school nurses, and classroom teachers have been professionally challenged by the presence of these students on public school campuses. Further, documentation of the challenges is present in current educational publications. Some teachers have expressed grave concerns when

they perceive they are expected to assist with or perform health-related procedures due to a current shortage or lack of school nurses. Their anxieties and frustration levels escalate proportional to increased role expectations. This study lends credibility and veracity to the importance of professional school nurse involvement with the health and safety of specialized health care procedures in public schools. Mandated legal changes and revisions to a lower student-school nurse ratio remain a top priority.

Nursing practice. The amount of time and energy invested by the participants in their daily practice with medically fragile students symbolized a significant level of personal dedication and professional commitment. In the beginning, when it became apparent that a medically fragile student might be attending school, the participants contacted family members, made home visits, and immersed themselves in the family dynamics of care. These situations assured a continuum of care with which the student was familiar and provided anticipatory knowledge and professional guidance to the school nurse. The recognition that parents represented the most important linkage to a successful school experience for these students also contributed to a successful school nurse experience. Reliance on professional knowledge, clinical expertise, and team collaboration were significant components of the professional school nurse role that supported an effective nursing practice. A multi-disciplinary approach proved to be an effective recommendation for problem-solving strategies in working with medically fragile students. The recognition of ever-expanding role responsibilities and professional demands encountered by the participants verified a need for continuing nursing education and specialized certification programs.

Concomitant with the aforementioned recommendations was an awareness of the need for self-care. Involvement with medically fragile students proved to be an exhaustive and stressful situation for many participants. An on-going vulnerability to respiratory infections and the bitter realities associated with imminent death were associated with many of these special needs students. When the inevitable loss of a child occurred, school nurses were involved with the grief cycle with families. Such experiences proved to be draining for participants, and a stated need for a supportive network emerged from the data. These findings indicate a need for school nursing practice to expand its self-care and self-preservation modalities. Support, solace, silence, and solitude may represent professional recommendations for effective school nursing practice.

Nursing education. This investigator's endeavor has provided an explanation of the scope of professional practice that defines the role of the school nurse working with medically fragile students. These findings have implication for the development of exemplary school nursing educational preparation. Support of graduate nurse specialty certification with strong theoretical and practical components remains a strong recommendation. In addition, mentor preceptors who are actively practicing and working with medically fragile students need to be included in the educational process. Exposure to varying school sites and student populations provides valuable professional readiness and significant cultural comparisons. A combination of intensive care techniques and specialized health care procedures integrated safely within the school environment is highly recommended. Adaptations to environmental exigencies should be included within

educational programs, and the reality of isolation and autonomous school nurse decision-making should be recognized and emphasized.

Education for school nursing practice can be enhanced by way of continuing education programs and peer support through professional organizations. Development of on-line electronic websites would facilitate the essence of communication and offer immediate access to professional opinions and suggestions.

Paramount to all the recommendations is the implications that nursing must step beyond the boundaries of nursing and collaborate with the disciplines of education, law, and politics to provide an effective educational experience for school nurses. School nurses are part of the global perspective of health care and their practice and expertise interfaces with members of the educational team and larger school community on a daily basis. A cross-pollenization and sharing of knowledge between education and nursing must include the components of law and politics.

Nursing research. Several implications and recommendations for research can be drawn from the study findings. The emergent theory of Connecting for Success is in need of further expansion and exploration. In addition, a replication of the study within different school districts would be important. Since the study involved one large urban school district, replication within a suburban or rural school district would provide interesting results. Likewise replication in a large urban district within a different geographical location would provide valuable results of a comparative nature.

The study represented an initial endeavor that involved only school nurses. Expanding the participants to include school administrators would provide valuable knowledge from a different perspective of special education and the prioritization of

health care on a public school campus. Also, further inclusion of students and their families would complete a triangulation of information that would surround this phenomenon.

Several linkages within the Connecting for Success theory need further exploration. Further research information needs to be obtained regarding the dimension of adapting the environment. Participants were involved with architectural modifications regarding access ramps as well as acquisition of hot water and bathroom facilities within classroom settings. This investigator feels quite certain there would be a plethora of additional adaptations involved with different geographical locations as well. The lack of electricity and the anticipation of auxiliary battery power was proactive thinking on the part of one participant. Similar circumstances could well exist in different settings in other studies.

The acquisition of professional knowledge and the utilization of clinical expertise were discussed with relevance to school nursing with medically fragile students. Are there areas of emphasis specific to elementary, middle, and secondary school settings? Are there comparable demands for expertise in other areas of nursing? What are the similarities of nursing qualifications amongst hospital, public health, and school settings? Are there other more specific qualifications that can be discovered in further research studies?

The third area of linkage that needs further exploration would be in the dimension of "Standing Out There." The presence of fear counterbalanced with professional autonomy represented an interesting combination of psychological components of the professional school nurse role. Is this combination unique to school nurses? What other

areas of nursing reflect these components? Are they considered facilitative or inhibitive to practice? In addition, further research into nurse role integration and role identity processes would be a strong recommendation emanating from the study.

The development of an instrument capable of measuring professional attributes would be an exciting addition to the field of school nursing research. This would inculcate a quantitative research component to the present phenomenon under study. Sufficient data regarding such a tool have yet to be obtained. Comparative analyses could be obtained from demographic information involved with nursing education, years of practice, and specific specialty credentials. Bivariate correlational statistical measurements would provide a starting point for this tool development. The results of this information would provide knowledge regarding the correlations between higher nursing education and the qualifications for specific specialty credentials. Outcomes of improved school nursing practice provided by such specialists would reveal further information and needed professional support. Recent literature has presented personal and professional characteristics of exemplary school nurses via questionnaires, but delineation of competencies needed for school nursing practice still requires further research.

A final recommendation for nursing research would involve the ethical dilemmas encountered in the care of medically fragile students within public schools. Compliance with legal mandates presents a moral consequence of inordinate time and attention given to one student to the neglect or possible detriment of many others. How does one justify the allocation of goods and services? What are the ethical priorities involved with medically fragile students on public school campuses? How far do the parameters of

responsibility extend for school districts? What is the definition of education versus respite care? An infinite listing of questions can continue, and a lifetime of nursing research can result from such an endeavor.

The study was conducted in order to provide an in-depth explanation and heightened awareness of the scope of the professional school nurse role in working with medically fragile students. Through the lived experiences of the participants, a complex multidimensional phenomenon emerged. It is anticipated by the investigator that the emergence of this theoretical model will help practicing nurses become aware of the dynamics of their school nurse role and the paradigm shift in nursing practice that has occurred. New knowledge to parents and other educational team members would include the importance of their participation and needed collaboration to ensure a positive school nurse experience. The aforementioned statement that unless something is known it cannot be valued or appreciated may well have direct application.

A new meaning of the role of school nurse now exists. A paradigm shift of school nursing practice has expanded to include intensive care/emergency room skills and advanced clinical expertise. Knowledge of these experiences can provide understanding and insights to improve the delivery and quality of school nursing care. The study establishes a trajectory of future research not only in nursing but also in the fields of education and policy development.

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Appendices

Appendix B

Consent to Act as a Research Interviewee

Appendix B

Consent to Act as a Research Interviewee

The perceptions of school nurses who work with medically fragile students

**Cay Chapman Casey, R.N., MSA, Ph.D(c)
Hahn School of Nursing and Health Science
University of San Diego**

I have been asked by Mrs. Cay Casey to be interviewed for a study of the perceptions of school nurses who care for medically fragile students. Mrs. Casey is a doctoral candidate from the University of San Diego and is conducting this study to find out ways in which school nurses perceive their work with medically fragile students.

I understand that the interview will take from 45 minutes to one hour and will be conducted in a place convenient to me. If it is agreeable with me, the interview will be audiotape recorded. I also understand that at any time I may quit the study and that if I decide not to participate, it will in no way affect my employment with the school district. I understand that I may ask questions before I sign this consent form and that later I can call Mrs. Casey at (619) 435-8770 about any questions I have concerning the study.

I understand that the interviews will be coded and locked up and that all information is confidential. Findings will be reported in such a way that my identity will not be revealed.

I realize that there are few or little risks to myself other than possibly being uncomfortable with some of the questions. If there is any question I do not wish to answer, I do not have to do so. I understand that the benefits from the study will be to medically fragile students and to those who help with their care.

I have received a copy of this form. There is no agreement, written or verbal, beyond that expressed in this form.

I, the undersigned, understand the above explanations and on that basis, I give consent to my voluntary participation in this research.

Signature of Subject

Date

Location

Date

Signature of Researcher

Date

Signature of Witness

Date

Appendix C

Interview Guide for the Perceptions of School Nurses

Who Work With Medically Fragile Students

Appendix C**Interview Guide for the Perceptions of School Nurses
Who Work With Medically Fragile Students****Code:** _____**Demographic Data:**

Name _____

Gender _____

Nursing Education _____

School Assignment _____ Longevity _____

Number of Medically Fragile Students _____

Comments: _____

Interview Guide:

- 1.) Tell me about the kind of medically fragile student you have in your practice?
- 2.) Give me an example of a situation in which things went well in your practice with medically fragile students?
- 3.) Give me an example of a situation in which things did not go well in your practice with medically fragile students?
- 4.) If you could decide, what would the ideal school nursing practice with medically fragile students look like?

Appendix D
Demographic Data

Appendix D

Demographic Data

Nursing Education

Baccalaureate in Nursing	10
Associate Degrees in Nursing	2
Masters of Science in Nursing	4
Masters of Science in Non-Nursing	2

Years in School Nursing

12.3 mean

0-5 years:	2
6-10 years:	3
11-15 years:	7
Over 20 years	3

Years with Medically Fragile Students

9 mean

0-5 years:	6
6-10 years	5
11-15 years	7

Nursing Composites

School Site-based Nurses	11 females, 1 male
Special Education Itinerant Nurses	6 females