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EXPLORATION OF SCHOOL ADMINISTRATOR ATTITUDES REGARDING
IMPLEMENTATION OF DO NOT RESUSCITATE POLICY IN THE
ELEMENTARY AND SECONDARY SCHOOL SETTING

A Thesis
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Science
in
Nursing

by
Martha Hone-Warren

June 2004


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June 2004

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ABSTRACT

Do Not Resuscitate (DNR) orders in the school setting are an emerging phenomenon. There are few school districts in the United States that have a policy regarding DNR orders in the school setting. Administrators are the gatekeepers of policy development and there is little known of administrator attitudes related to DNR orders in the school setting. School nurses need to understand administrator attitudes in order to facilitate DNR policy development.

This investigation explored the attitudes of 15 administrators about DNR orders in the school setting by individual, structured interviews. Administrators were interviewed about their feelings related to DNR orders in the school setting and about DNR policy implementation.

The majority of administrators felt that DNR policy should not be developed for the school setting due predominantly to the extreme emotions involved and lack of administrator training related to DNR orders. The majority of administrators did agree that having a DNR policy would clarify how staff should respond to DNR orders at school.

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Lastly, I would like to acknowledge two nursing colleagues and friends, Barbara A. Collins, MSW, RN and Kathleen Winston, DNSc(c), RN, for their constructive feedback and support throughout the thesis process.

DEDICATION

I would like to dedicate this thesis to my husband Michael J. Warren, my son Samuel M. Warren, my mother Harriet C. Hone and my sister Beth A. Melonuk. I am deeply grateful for their love, support and encouragement.

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CHAPTER ONE

INTRODUCTION

Background

Nurses have been in American public schools since 1902 (Wald, 1915). Lillian Wald, a public health nursing pioneer, and the founder of the Henry Street Settlement in New York, offered Lina Rodgers the opportunity to become the first public health nurse to work in the school setting (Pollitt, 1994). The focus of this first school nurse was preventing the spread of communicable diseases, hygiene and school truancy. The school nurse visited the homes of students excluded from school due to infectious diseases to insure treatment. Treatment was essential to decrease absenteeism due to illness and hygiene and to keep children in school so they could learn (Grant, 2001; Wold, 1981).

The objective of the school nurse remains essentially the same today; to assure that students enter classrooms free of communicable diseases and in optimal health, which increases attendance. However, the objectives of freedom from communicable diseases and optimal health have both been altered by changes in the law and by changes in health care for children (Pitman, Wolfe, & Selekman,

2002). These changes have influenced the objectives of the school nurse.

Significant legislative changes, including the Rehabilitation Act of 1973; the Individuals with Disabilities Act (IDEA) of 1975, and IDEA Amendments of 1997, have also directed the course of school nursing. These two laws have influenced school nurse practice by legislating that disabled children are eligible to attend public school. IDEA stipulates that all eligible children with disabilities receive a free and appropriate public education in the least restrictive environment appropriate to their needs (IDEA, 1997). IDEA also requires public schools to develop an Individualized Education Plan (IEP) for each child that requires special education services because of their disability. The specific nature of the educational service is outlined in the IEP and is related to the disability (Smith, 2000). The school nurse now works closely with a variety of disabled students and their families, in addition to working with other students to eradicate communicable diseases and to promote optimal health.

Scientific and technological advances have influenced school nursing too. Children who, in the past may have died as infants are now living longer and are attending

school. Students with diverse health conditions needing all levels of care are entering public schools (Pittman et al. 2002) and school nurses are caring for them.

The laws enacted in 1973, 1975 and 1997 entitle children who are medically fragile to attend public school despite their medical disability (Passarelli, 1994; Schultz-Grant, Young-Cureton, & Kataoka-Yahiro, 1998). In 1999 the Supreme Court, in Cedar Rapids Community School District v. Garret F, upheld that schools are financially responsible for providing nursing services for medically fragile students. Medically fragile students are now part of the general and special education community. Ten to 15 percent of school-aged children have ongoing health care problems, while 1 to 2% have severe, chronic illnesses including end stage heart, liver and kidney disease, cancer, progressive neurological disorders, muscular dystrophy, and AIDS (McHenry, 2000). Some of these medically fragile students with life-threatening diseases may have had a Do Not Resuscitate (DNR) order in the hospital due to their illness and may wish the DNR order to be honored within the school setting. For example, the student with muscular dystrophy has a medical diagnosis that will not respond to life-sustaining intervention, that is, CPR. Any attempts at resuscitation could cause

the student to suffer more harm than good (Costante, 1998).

Throughout the country there is inconsistency regarding the laws that allow for a DNR order outside of a hospital (Sabatino, 1999; Miller-Thiel, 1998; Seawell & Balkman, 2002; Thomas & Hawke, 1999). In 1989 there were only eight States in the United States that had policies that allowed for DNR orders outside the hospital and only one of those states had a statute. By 1999 there were only eight states that did not have statutes or policy to address the issue (Sabatino, 1999). Some states in the country do not have laws in place that would support a DNR order in any community setting, let alone the school setting. At this point in time DNR orders in the school setting have either been incorporated into policy that allow the student the right to die, or, incorporated into policy that refuses any consideration of such action. Most school districts have no policy at all. In 2000 only 9.2% of school districts required health services staff to follow DNR orders (Brenner et al. 2001).

The National Association of School Nurses (NASN Position Statement, 2000), The California School Nurse Association (CSNO Position Statement, 2001), the American Academy of Pediatrics (AAP Policy Statement, 2000) and the

National Education Association (NEA Policy Statement, 2003), maintain a neutral position regarding DNR policy development and defer that decision to the local school district. All these organizations state that if school districts develop policies that honor DNR orders, specific procedures need to be developed to implement policy. All these organizations outline criteria that need to be included in procedural development. The responsibility for policy development rests with the local school district. Policy development is occurring very slowly at the local school district level. Few school districts have dealt with DNR orders in the school setting, most districts choosing to ignore the needs of the medically fragile student and some districts denying that the needs even exist (Schultz-Grant et al. 1998). Medically fragile students have the legal right to be at school, to be physically cared for at school and, for some, that care may extend to end-of-life choices by the student and the student's family (Rushton, Will, & Murray, 1994).

Statement of the Problem

DNR orders in the school setting are a relatively recent occurrence. They are also an infrequent occurrence.

Nevertheless, the DNR order is a possible outcome for some medically fragile students.

Most school districts do not allow for the death of a student on site. The idea of not resuscitating students at school is a frightening and new experience for most school districts but it is a situation that will have to be faced eventually (School Nurse Alert, 1999). It is an issue whose time has come (Rushton et al. 1994).

Purpose of the Study

No previous study has attempted to clarify and articulate administrator attitudes regarding DNR orders in the school setting. Administrative school staff are responsible for development and implementation of school policy therefore understanding administrator attitudes would assist discussion and decision making related to DNR orders in the school setting. Schultz-Grant et al. suggested studying administrator attitudes in 1998 as a useful further examination of DNR orders in the educational setting. Understanding administrator attitudes towards DNR orders in the school setting will assist the school nurse in knowing how to approach the administrator to initiate discussion about developing and implementing policy for DNR orders in the school setting. Addressing

administrator attitudes towards a DNR policy in the school setting will further clarify and articulate administrator responses towards this issue and may ultimately safeguard the medically fragile students' right to self-determination by the development of policy that would allow DNR orders in the school setting.

Limitations of the Study

This study was conducted within one school district in southern California, limiting its generalizability to other school districts. The study questioned 15 of 64 administrators within this district. It cannot be known if these 15 administrators are representative of all administrators in this school district. The study does not examine staff members regarding their attitudes towards DNR orders in the school setting. Interviewing staff would further add another dimension to an examination of DNR orders in the school setting.

Theoretical Orientation

Watson's nursing Theory of Human Caring (also called the Theory of Transpersonal Caring) is the theoretical orientation for this study. One of the assumptions of the Theory of Human Caring is that human caring is the moral ideal and origin of the professional nurse's role and is

the nurse's *calling*. According to Watson, the ultimate goal of nursing is protection, enhancement, and preservation of human dignity and humanity (Fawcett, 2000).

An obligation exists to care for the medically fragile student at school. This obligation may, for some students, include honoring the conclusion of their illness by allowing them to die with dignity in the school setting. The ultimate goal of nursing as human caring is to protect, enhance and preserve human dignity. The school nurse response to DNR orders in the school setting would be: (a) to protect the wishes of the student and family related to a DNR order in the school setting (b) to enhance all the steps of procedure related to DNR in the school setting and (c) to preserve the human dignity of the student and family throughout the process of death.

Definitions of Terms

Advance Directive - An advance directive is written documentation that tells what a person wants or does not want if he/she, in the future, cannot make his/her wishes known about medical treatment. An advance directive may include a do not resuscitate order but advance directives and DNR orders are not

synonymous (Walter Reed Hospital Patient Information, 2004).

Do Not Resuscitate Order - A do not resuscitate order allows a patient with a life threatening illness or injury to forgo specific resuscitative measures that may keep them alive. These measures include: chest compressions (CPR), assisted ventilation (breathing), endotracheal intubation, defibrillation, and cardiotoxic drugs (drugs which stimulate the heart). Do not resuscitate orders do not affect the provision of other emergency medical care, including treatment for pain (also known as "comfort measures"), difficulty breathing, major bleeding, or other medical conditions. The DNR order is a written authorization by the student's physician and accompanied by parental authorization for the school aged child (California Emergency Medical Services Authority, 2003).

Individualized Education Plan - The individualized education plan is a quasi-contractual agreement to guide, orchestrate, and document specially designed instruction for each student with a disability based on his or her unique academic, social, and behavioral needs (ERIC Digest #E600, 2000).

Medically Fragile Student - A medically fragile student is in the age range of birth to 22 years; and, has serious, ongoing illness or a chronic condition that has lasted or is anticipated to last at least 12 or more months or has required at least one month of hospitalization, and that requires daily, ongoing medical treatments and monitoring by appropriately trained personnel which may include parents or other family members; and, requires the routine use of medical device or of assistive technology to compensate for the loss of usefulness of a body function needed to participate in activities of daily living; and, lives with ongoing threat to his or her continued well-being (Public Education Information Management System, 2000).

Life Threatening Illness/Injury - A life threatening illness is medical condition that is a danger to the life of a person.

School Nurse - A school nurse in California is a baccalaureate prepared Registered Nurse, in possession of a Public Health Nurse certificate, who is credentialed by the California State Board of Education to work in the school setting.

School Nursing - School nursing is a specialized practice of professional nursing that advances the well-being, academic success, and life-long achievement of students. To that end, school nurses facilitate positive student responses to normal development; promote health and safety; intervene with actual and potential health problems; provide case management services; and actively collaborate with others to build student and family capacity for adaptation, self management, self advocacy, and learning (NASN, 1999).

CHAPTER TWO

REVIEW OF THE LITERATURE

The Literature

The literature review includes a discussion of school nursing and the laws that have impacted school nurse priorities related to the medically fragile student. Articles that discuss the historical development of laws, statutes, and policy surrounding out-of-hospital DNR orders are also examined. This literature review will conclude with articles that outline the school nurse response to DNR orders in the school setting, including literature that supports this current study.

School Nursing

Four authors discuss the history of school nursing in the United States. Chapter 3 from Lillian Wald's *The House on Henry Street* (1915) outlines the evolution of public health nursing in the school setting. This chapter is particularly enlightening regarding the motivation and thinking of Wald about public health and regarding the beginnings of public health nursing in the school setting.

Wald states about the beginnings of school nursing, "Examination by physicians with the object of excluding children from the classrooms had proved a doubtful

blessing. The time had come when it seemed right to urge the addition of the nurse's service to that of the doctor. My colleagues and I offered to show that with her assistance few children would lose their valuable school time and that it would be possible to bring under treatment those who needed it" (p. 50,51).

Pollitt (1994) offers a biography of the first school nurse in the United States, Lina Rodgers. Rodgers' connection to Lillian Wald and the Henry Street Settlement, the nature of the work of the first school nurse and Rodgers' contribution to school health is all discussed. Rodgers often visited the homes of school children who were sick. She would teach the family about treatments needed for the child and helped the family obtain supplies or equipment. Rodgers' efforts reduced absenteeism at the schools in which she worked.

Grant (1937, 2001) reviewed the historical facts of school nursing and the need for school nursing in this article from the 1930's. Grant outlines school nurse services, many of which have remained the same from 1937 until the present, "She interprets the child's need to the parents and teachers, and uses her knowledge of community resources to help them to receive proper treatment, medical advice, home care, and school care. She brings to

the school information about home conditions which help in understanding the child's behavior, and physical appearance" (p. 388), wrote Grant.

A school nursing text by Wold (1981) shares information about nursing history in total, along with the beginnings of school nursing in the United States. In addition, the text offers comprehensive instruction related to school nursing practice.

Wold (1981) offers, along with other school nurse information, a discussion about school nursing research and why is it needed. Wold states that when school nursing research documents outcomes, clarifies role expectations and develops new approaches to student health needs, then that research can improve the public image of all nurses as well as improve services to students.

A discussion of current school nursing services by Pitman et al. (2002) provides a brief history of school nursing in the United States, outlines the major laws and legal developments that have changed the course of school nursing in the last 30 years and discusses the expanding role of the school nurse.

Pitman (2002) delivers an excellent outline of current school nurse practice. The article confronts the stereotyped school nurse image of the past and describes

the advanced practice that school nursing actually is today. For example, school nurses now have to have technical expertise related to a number of specialized procedures such as suctioning, catheterization, gastrostomy tube feedings, and blood glucose monitoring. The school nurse needs to know a variety of protocols and equipment used by numerous providers. The school nurse writes Individualized Health Plans (IHP) for children with chronic conditions. The present day school nurse is also a case manager, making referrals, following up on referrals, attending to staff wellness and the overall safety of the school site.

A School Health Policies and Programs Study (SHPPS) for the year 2000 (Brener et al. 2001) shares detailed statistics from a systematic random sample of data from all 50 states about health services programs available to students in elementary and secondary education in the United States. Data from Brener et al. is particularly useful as it represents the only statistical information found in the literature regarding how many school districts in the United States have DNR policy.

Passarelli (1994) describes issues that school nurses will address in the future. The challenges faced by school nurses today are the trends identified by Passarelli 10

years ago. The article discusses the history of school nursing and then current school nurse practice. Technology, changing disease trajectories (progression towards more chronic illness), leadership through collaboration and client health care outcomes are all outlined as trends. Passarelli (1994) states that as chronic health conditions will impact health services provided by school nurses, due to the increase of chronic diseases in the school setting, there will be a need for the school nurse to have greater knowledge and skill in caring for these students with complex medical problems.

The United States Department of Education (2004) discusses the history of the IDEA on their web site. IDEA began in 1975 as the Education for All Handicapped Children Act (Public Law 94-142) and is currently enacted as IDEA, amended in 1997. The article outlines the initial purposes of IDEA including the statement that all children with disabilities have available to them a free, appropriate public education. Changes to the law from 1975 until now are reviewed including mandated services for infants, toddlers and preschool children and culturally relevant instruction as examples. The history of IDEA review offers the reader a succinct history of IDEA and its evolution.

Smith (2000) developed a resource guide available to educators about IEP Programs. The article lists particular information needed in the IEP such as current levels of educational performance, special education and related services, dates and locations of services to be provided and statements of transition services. Smith also lists participants needed at an IEP meeting including the student, a parent, special education teacher, regular education teacher, agency representative and any other agency personnel who have knowledge that best serves the student's needs. The school nurse is considered an agency person who has knowledge that best serves the student's needs. This article is a good resource for educators requiring more information about the IEP meeting process.

Laws Related to Do Not Resuscitate Orders in the School Setting

Sabatino (1999) detailed the results of a comprehensive national survey conducted in 1999 regarding current State non-hospital DNR law, detailed the development of draft profiles of State law and detailed a state check for draft accuracy and correction. Sabatino (1999) reviews the background related to the development of DNR orders in the non-hospital setting. Sabatino (1999) details specific information about DNR non-hospital laws

in each state, the impact of state law on emergency medical services (EMS), variations from state law to state law and discusses current issues and problems related to DNR orders in the community setting. For example, the discussion about the language of the phrase "do not resuscitate," which is perceived as predominantly negative, is offered with a recommendation to change the language possibly to comfort care measures. The details of this article provide a broad perspective regarding non-hospital DNR orders.

Educators Sewall and Balkman (2002) discuss DNR orders in the school setting. There is a potential conflict between DNR orders and state/federal laws. A potential conflict exists regarding whether school personnel are protected (or not) under their state law for complying with DNR orders. The authors review the laws regarding parent rights and DNR orders and also the laws of 21 states pertaining to DNR in the school and/or community setting. District personnel are encouraged to follow a DNR order regardless of state law otherwise employees and their school districts could be left open to litigation under IDEA, Section 504, or the courts.

Sewall and Balkman (2002) articulate the inconsistency among states regarding DNR orders and say

that the need for policy and procedure is fundamental. The review of state law is confusing, adding to the argument about inconsistency and DNR implementation. This article strongly encourages the education community to honor DNR orders and to understand a DNR order as a legal document.

Thomas and Hawke (1999) also educators, reviewed DNR orders as one of many health care services provided to children in the school setting. This article about mandated health care services in the schools includes a section covering DNR and explains to educators that most states will not consider them legally liable for not following DNR orders. Thomas and Hawke offer a contrasting educator perspective from Sewell and Balkam.

Most acute care facilities, such as hospitals, have policies and procedures that address in-house DNR orders (1998). Miller-Thiel (1998) polled State Emergency Medical Services regarding whether or not a DNR form or process is available to EMS personnel for the community setting (school and/or home), if so, whether the form or process applies to minors, and, if not, whether states have legislation pending that would require the development of said form or process. Not all states have a DNR form or process for the community setting, some states have a DNR form or process for adults but not minors in the community

setting and some states have neither. Also, some states have legislation pending but not all.

Miller-Thiel (1998) clearly demonstrates the ambivalence in the nation about DNR orders outside the acute care setting, especially regarding children. Miller-Thiel discusses the need for a comprehensive approach to developing DNR guidelines within all states to meet the need of a small but growing number of the population who are children who will require a DNR order within the community setting.

The National Education Association (NEA) policy (1994) regarding Do Not Resuscitate orders reiterates previous information about the inconsistency of individual states in their approach to DNR in the schools. The NEA does not address whether districts should honor DNR requests (that should be discussed with local counsel) but does address a course of action if the district decides to honor the DNR order. Of all the policy statements, the NEA policy is the only one to state the importance of providing death and dying in-services for students.

The American Academy of Pediatrics (AAP) *Do Not Resuscitate Orders in Schools (RE9842)* (2000), recommends that a team of professionals, including the physician, the school nurse, and school district staff develop a plan

that suites the needs of the local district so as to avoid confrontation and litigation. The policy includes a discussion articulating DNR as part of the appropriate and continuing health care for some students. It also clarifies that such a decision can create turmoil in the school setting where the death of one student could impact other students. The policy clearly outlines two points of view and is helpful in that regard however there is no discussion on how communication between parties can be initiated.

School Nurse Response to Do Not Resuscitate Orders in the School Setting

Schultz-Grant et al. (1998) surveyed 214 school nurses who attended an annual California state convention to gather information about Advance Directives (ADs) and DNR in the school setting. The authors wanted to know what knowledge school nurses' had about ADs and DNR orders, school nurses' current practice regarding ADs and DNR, and school nurses' feelings and beliefs about ADs and DNR which would impact school nurse practice. This descriptive, correlational study found that the nurses with Master of Science in Nursing (MSN) degrees were more informed regarding ADs and DNR than those with bachelor's degrees, that school nurses found it difficult to speak

with families about ADs and DNR as so few districts have policies in place that would allow them to do so, and, that school nurses exhibited some conflict regarding end of life issues. The authors presented very helpful statistical data about DNR in the school setting. It points the way to future research, suggesting studies with other school district staff such as teachers and administrators.

A discussion article by Costante (1998) reviewed the history of DNR in the school setting, the inconsistent legal response throughout the country to allowing DNR in the school setting, and the development of DNR policy and procedure for the school setting. Costante believes that the school nurse should initiate policy and procedure development and provided detailed steps and lists for both. Although Costante gives very detailed steps to follow for setting up policy and procedure, no information is shared about how the school nurse initiates policy and procedure or how the school nurse helps staff articulate feelings, beliefs and values about DNR orders, those who presumably would become part of the team to develop policy and procedure.

In a presentation to the International Special Education Congress 2000, McHenry (2000) focuses on DNR in

the school setting as one appropriate response to caring for the medically fragile student. The history of DNR in the school setting in the United States is reviewed and factors to consider while developing procedure are listed, such as determining the procedure to be followed if there is a respiratory or cardiac arrest in the school setting, providing an in-service for staff about what to expect and interfacing with local EMS. Some tools are shared, such as books to read to younger children to help them discuss the death of a classmate, to assist schools as policy and procedure are developed. A statement is made that acknowledges the psychological response of school district personnel regarding the impact of a child's death, however no suggestions about how to help district personnel begin the feeling exploration or articulation were mentioned.

A discussion article by School Nurse Alert (1999) provides a brief overview of the current situation regarding DNR orders in the school setting. The article states that the challenge of DNR orders in the school setting will eventually have to be dealt with, despite fear and resistance by school personnel. The situation is reminiscent of the 1970s after Public Law 94-142 was implemented. Disabled students were to be integrated into regular education campuses at that time and there was

great resistance to the process as there is now towards DNR orders in the school setting.

The National Association of School Nurses (NASN) Do Not Resuscitate Position Statement (1994) suggests that the local school nurse will need help from administrators, parents, physicians, teachers and the student where appropriate, if a plan for DNR in the schools is to be developed. In addition, the NASN defers all decisions regarding DNR to the local level and its legal council. An Individualized Health Care Plan (IHP) and an Emergency Plan would need to be developed by the local school nurse. It is helpful that the NASN has articulated for school nurses that there may be DNR orders introduced to the school district but the NASN provides no guidance about how the school nurse is to participate in such a change if an order is received.

The California School Nurse Association (CSNO) statement regarding Do Not Resuscitate policy echoes that of the NASN policy. CSNO defers policy development to the local school district, provides procedural guidelines if policy is developed and emphasizes a team approach for both of the above.

CHAPTER THREE

METHODOLOGY

Design of the Investigation

This descriptive, qualitative investigation was designed, via a structured interview, and using grounded theory methodology, to articulate elementary and secondary school administrator attitudes about DNR orders in the school setting. An interview schedule was constructed to examine administrator attitudes regarding DNR orders in the school setting. Three doctorally prepared nurse educators assessed the interview schedule for content validity. The interview items explored participant personal feelings about DNR orders, attempts to discover participant attitudes about DNR orders in the school setting and then concludes with an examination of DNR policy implementation.

Table 1. Interview Schedule

Interview Schedule	
1.	What is your understanding of a Do Not Resuscitate order?
2.	What are your personal feelings related to having Do Not Resuscitate orders in the school setting?
3.	What do you see as advantages to developing a Do Not Resuscitate order in the school setting?
4.	What do you see as barriers to the development of a Do Not Resuscitate order in the school setting?
5.	Which individuals do you think should be part of the process of developing a Do Not Resuscitate policy?
6.	What should be the process of beginning policy development?
7.	How do you see a Do Not Resuscitate policy being introduced within the school district community?
8.	How do you see a Do Not Resuscitate policy being introduced to the local community?
9.	How would federal and state laws regarding Do Not Resuscitate orders in the school setting impact your decision to institute Do Not Resuscitate policy development?

Participants

A convenience sample of administrators from a local Southern California school district was invited to participate in the investigation. This school district currently does not have a DNR policy and is not in the process of developing one. The participants included representatives from the highest level of administration down to entrance level administrators. Participant demographic data only included years of work as an

administrator. Collectively the group represents 244 years of administrator experience. No other demographic data was collected to protect participant confidentiality.

Data Collection Procedure

This study was reviewed and approved by the California State University San Bernardino Institutional Review Board (CSUSB IRB). Seventeen individuals were contacted for an interview. All individuals were contacted face-to-face, by phone or by e-mail. The purpose and process of the study was explained to the potential participant at the time of initial contact. After the potential participant agreed to be interviewed, a date was set for interview and a packet of informational papers was sent to them. The packet included the following; (a) the schedule of questions about which the participant would be interviewed, (b) an informed consent form, (c) a copy of the CSUSB IRB approval letter, (d) a copy of the letter from the local school district superintendent to CSUSB IRB granting permission for the investigator to interview administrative staff, and (e) a copy of the investigator's completed Human Participant Protections Education for Research Teams certificate granted by the National Institutes for Health. A confidential place was requested

for interview, one that would afford the fewest interruptions. Most often the office of the participant was chosen to be the site for the interview. The participant chose the date and time for the interview. The time allowed for interview was from one to two hours. It was explained to each participant that the investigator would be taking notes throughout the interview. In order to reduce any introduction of bias into the interview process the investigator did not offer information about DNR orders to the participant unless a question was asked. This was explained to the participant at the beginning of the interview. Any information given the participant was given after all the questions were answered or after the participant had completed a response to a particular question. A thank you note was sent to each participant after the interview.

Data Analysis Procedures

During the interview participant responses to the questions were handwritten. Handwritten responses were typed after the interview. A conscious effort was made to write responses as they were spoken and to copy responses as they had been handwritten, without editing the spoken word. Open coding and constant comparison were used

throughout the interview process in order to generate themes and patterns from the responses. Memos were also used throughout the process in an attempt to reveal any underlying assumptions on the part of the investigator.

CHAPTER FOUR

RESULTS AND DISCUSSION

Presentation of the Findings

Introduction

Fifteen of the 17 administrators initially contacted agreed to participate in the study. At the time of interview most of the participants stated they had reviewed the study questions prior to the interview; two participants had researched the topic on-line prior to interview. A question was asked at the beginning of every interview that had not been included in the list of questions initially given each participant. The question asked was, "What is your understanding of a Do Not Resuscitate order?" This question helped clarify participant familiarity with DNR orders and outlined any personal experience they may have had with DNR orders. The time needed to write participant responses encouraged an opportunity for further reflection upon the part of the participant. Often additional responses to questions were provided after a moment of silence. The average interview time was 45 minutes to one hour. Each participant was asked at the end of the interview if the investigator could contact them again, if need be, to clarify any of

their responses to the questions. All of the participants agreed to be contacted at a later date by the investigator if necessary.

Question One

Question One asked of participants was not on the question sheet provided them ahead of time. This was done deliberately to stimulate initial discussion about DNR orders. Question One asked, "What is your understanding of a Do Not Resuscitate order?" Some participants understood the question as asking for a personal experience with a DNR order. For them, personal experience equaled familiarity with a DNR order or understanding of a DNR order. Others discussed what they understood a DNR order to mean and did not share a personal experience about a DNR order. And, others shared both an understanding of what a DNR order means and a personal experience related to a DNR order. At least one person shared their feelings about having DNR orders in the school setting in Question One, which really is a response to Question Two.

Familiar. Eight participants stated that their familiarity with DNR orders is due to an elderly relative that had a DNR order prior to death. Of these, all were considered successful events except one. Participant #4 had a relative whose DNR order was not honored. Three had

fathers that had a DNR. One mentioned a father's death but not that the father had a DNR. Only one participant had a child with a serious injury where death was a possible outcome but consideration of a DNR was never necessary. Not one of the participants has ever seriously considered a DNR for a child or young adult.

Understanding of Do Not Resuscitate Order. Five of the participants understood a DNR order to mean withholding CPR. Participant #4 understood the legal nature of a DNR order and stated, "it is a legal document signed by an individual indicating a choice not to have life support measures administered if even the medical condition calls for it." One participant believed a DNR order to be an order a parent can file with the school that allows the parent to make the decision regarding whether or not to call 911 for their child. Three other participants also spoke about their understanding of the process of implementing DNR orders at the school site. "This would happen where there is a disease or disorder that is possibly life threatening," said participant #12.

Participant #14 understood that a DNR order spoke to quality of life and "allows the terminally ill to die peacefully and with dignity; you don't want to prolong life unnecessarily if there is no quality to life."

Not Familiar. Three of the participants were not familiar with DNR orders. One of these participants thought the interview topic was Cardio Pulmonary Resuscitation (CPR) and throughout the interview continued to confuse DNR with CPR.

Personal Advance Directive. Two of the participants have ADs for themselves. Participant #11 stated that it is "entirely appropriate to have an advanced directive or DNR order for oneself." Participant #11 does have a personal advance directive. Of those participants who do not have a DNR order for themselves, three said, "I would consider one if I became a burden or did not have quality of life" (Participants # 1, 2, & 5).

Table 2. Question One

Participant Understanding of/Familiarity with DNR orders	Number of times mentioned by participants*
Familiarity with DNR orders due to death of a relative who had a DNR order	8
Understanding of DNR orders:	10
Understand to mean withholding CPR	5
As a legal document	1
To die with dignity	1
As a procedure within the school setting	3
No Understanding/familiarity/personal experience with DNR orders	3
Participants with personal advance directives	2

*Numbers may reflect multiple responses from individual participants

Question Two

Question Two asked participants, "What are your personal feelings related to having Do Not Resuscitate orders in the school setting?" Most participant feelings were that DNR orders should not be in the school setting.

Extremely Emotional. One of the reasons that participants gave for feeling that DNR orders should not be in the school setting is that a child's death is "extremely emotional." Participants #7 said, "It would be a significant emotional impact on the teacher." "I think it is horrendous," says participant #15. "Obviously a sensitive subject," (participant #5) and "very difficult situation, I would feel like I had abandoned the child," said participant #6. Eleven participants mentioned emotion as one reason why DNR orders do not belong in the school setting.

Educator Training. Another reason given as a personal feeling about not having DNR orders in the school setting was educator training and/or educator identity. Seven participants mentioned this aspect of personal feeling about DNR orders in the school setting. Participant #1 stated, "Beyond the purview of an educational professional to follow the order itself." "We're not capable of making those decisions, even with an MD order; I just don't think

it is my place," said participant #2. Participant #4 said, "You take people who deal with life-teachers-and then go to death; that's quite a stretch!" "We're not health care providers; we can't make that decision; we don't have the training," from participant #7.

Response to Student's Death by Other Students. Some participants were worried about the responses of parents and other students to the death of a student at school. Participant #5 said, "Children may have fears, they might be wondering, 'Would they save me?'" And participant #6 stated, "Could you imagine the dialogue going on around, 'Aren't you going to do CPR?'" "You'd have to deal with the questions of the kids and the parents, 'Why didn't you do something?'," said participant #7. Three participants were concerned about student and parent response to a student death at a school site.

Burden on School Staff. Still another reason mentioned by three participants for feeling DNR orders do not belong in the school setting are that they place a burden on school staff, "even to grant the possibility of that happening at school" said participant #1. "My plate is full, I don't need this, thank you," said participant #2.

Do not Believe in Do Not Resuscitate Orders.

Participant #4 stated, "I don't believe in them" when asked about feelings related to DNR orders in the school setting. Participant #4 continued, "I'm shocked that parents can write DNR orders for children." Participant #9 said, "If you believe it's OK, then OK; if you believe in resuscitation a DNR order completely flies in the face of having resuscitation not done."

Believe in Do Not Resuscitate Orders. Two participants believed that having DNR orders at school are appropriate. The reason they gave was personal experience with near death.

Honors Parent Intent. Participant #11 felt that a DNR order was "probably appropriate under certain circumstances, it is a family decision that is made as a public statement, in that situation you have to respect that right." And again, "parents who have gone through this have a reason and it needs to be respected," from participant #12.

Fear of Litigation. Fear of litigation was another feeling given why participants would not want DNR orders in the school setting. One participant mentioned the freedom not to be sued; participant #14 stated that if a DNR order was misunderstood and a mistake was made

interpreting an order that the potential to erode a career was "huge."

Confidentiality. Confidentiality, or the lack of it, was also a reason for not feeling DNR orders are appropriate in the school setting. This was a concern of participant #1.

Table 3. Question Two

Participant feelings related to having DNR orders in the school setting	Number of times mentioned by participants*
Extremely emotional	11
Lack of educator training	7
Negative response to student death by other students	3
Burden on school staff	3
Do not believe in DNR orders	3
Believe in DNR orders	2
Honors parent intent for child	2
Fear of litigation	2
Confidentiality	1

*Numbers may reflect multiple responses from individual participants.

Question Three

Question Three asked of participants, "What do you see as advantages to developing a DNR order in the school setting?" There were five particular responses to this question from participants.

Clarity for Staff. The first reason given was that a DNR order makes it clear to staff what to expect if there is a DNR order at the school site. Seven participants gave

this as an advantage to developing a DNR order in the school setting, "Any time you have a clear directive it makes action objective," said participant #6 and participant #5 said, "it makes clear for school personnel what action to take." Participant #8 stated, "You wouldn't be caught by surprise." And participant #14 said, "If it is written, if communicated, the administrator can relax, they don't have to guess." "Certainly would take the guesswork out of the procedure; staff would be familiar with it and it would eliminate the potential of doing something incorrectly" was the response of participant #15.

Respecting Family Wishes. Participant #11 believed the advantages include respecting family wishes and meeting the needs of the child. Respecting family wishes is the second most articulated reason seen as an advantage to developing a DNR order in the school setting.

Meeting the Needs of the Student. Only one participant spoke about meeting the needs of the child as an advantage to developing a DNR order in the school setting.

Consistency Within the School District. Two others said having an order in the school setting would increase consistency within the school district.

No Advantage. Four participants stated they saw no advantage to developing a DNR order within the school setting. Participant #4 said, "No advantage to dealing with the subject." The other responses were, "None" (participant #7, "No advantages for faculty or staff, no advantage for the parent" (participant #9), and "Can't think of any advantage; no practical application," from participant #1.

Table 4. Question Three

Advantages to developing DNR orders in the school setting	Number of times mentioned by participants*
Clarity for staff	7
Respects parent wishes	5
Consistency within the school district	2
Meets the needs of the student	1
No advantage to developing DNR orders in the school setting	4

*Numbers may reflect multiple responses from individual participants.

Question Four

There were 12 responses articulated by administrators to this question. The responses have some similarities to the responses in Question Two about administrator feelings towards DNR orders in the school setting.

Ethical/Moral Dilemma. "Values, morals, religion, you can add ethics if you want; you're taking on religions and the religious community would have to weigh in" was the

response by participant #4. Participant #1 said, "There would be philosophical differences between those who agree with the order and those who believe the order to be morally inhumane." "It's an ethical dilemma; trying to get a group or the Board (of Education) to agree with stakeholders or the community; finding consensus on the issue" (participant #14), "mixed beliefs of staff" (participant #8), "personal beliefs are a wide range" (participant #9) and participant #11 said, "It's the philosophical, ethical, moral questions regarding the family's right to make this determination for the child; emotions are involved."

Lack of Training. Seven participants mentioned training as another barrier to the development of a DNR order in the school setting. "Scope of DNR order is broader than the knowledge of most school employees, it requires very thorough training regarding responsibility (of employee)," stated participant #1. "We're not medically prepared to make a decision" (participant #2) and "Qualification of staff, is this a time a DNR is needed or a time for a band-aid?" asked participant #8.

Emotional Situation. Again, the emotional response to a DNR order was considered a barrier in the school setting. "Educators are helpers, in general, and it would

be difficult; the whole domain of talking about death and children is near taboo, an emotionally laden issue and can cause conflict and stress," said participant #9.

"Emotional conflict for staff," from participant #7. And participant # 13 said, "Probably people like me or other people on staff who do not understand this stuff: it deals with people's feelings and feelings aren't rational."

Litigation. Fear of litigation was another echo from the responses to Question Two. "Legal implications and interpretation of the laws" from participant #7 and "liability aspect is huge and based on human decisions/human error," from participant #8.

Administrator Difficulty. Participants spoke to the difficulty they could have as administrators as a barrier to having DNR orders in the school setting. "I don't want to be in that line of fire" from participant #4 and participant # 13 said, "afterwards you would have to deal with other students and parents; it's a hard situation for an administrator as you're dealing with all the fallout."

Miscellaneous Barriers. Other reasons participants gave as barriers to the development of a DNR order in the school setting were: (a) the fear that the student with the DNR order may be excluded from school, removed from general education, because of the fear of death occurring;

(b) The sense that "This doesn't happen; in a million years this hasn't come up and it's not a fun topic" from participant #15; (c) Paramedics who do not want to stop resuscitation; (d) Wanting to know what the child with the DNR order feels about the order; (e) what if they didn't want it?; (f) Participant #9 said, "The parent's wishes fly in the face of the education process"; and, (g) from participant #12, "If family does not speak English that could be a barrier."

No Barriers. Participant #10 felt there are no, "none," barriers to developing a DNR order in the school setting. A DNR order makes sense to this participant as long as the procedure is thoroughly explored by everyone; that it was completely spelled out.

Table 5. Question Four

Barriers to the development of DNR orders in the school setting	Number of times mentioned by participants*
Ethical dilemma	7
Lack of staff preparation	7
Emotional situation	5
Fear of litigation	4
Difficulty for administrator	3
Student could be excluded from school	1
Denial that a student death could happen	1
Paramedics might begin resuscitation	1
Concerns regarding whether the child has been involved with own DNR order	1
"It flies in the face of the education process"	1
Non-English speaking family might not be able to make their wishes known regarding DNR order	1
No barrier to the development of a DNR order in the school setting	1

*Numbers may reflect multiple responses from individual participants.

Question Five

This question asked participants who they thought should be part of the process of developing a DNR policy. The following table outlines their responses. Parents and administrators are seen as the most important individuals to be involved with beginning policy development. After that are medical consultants and lawyers. The numbers suggest that parents, consultants and lawyers are essential for this policy development.

Table 6. Question Five

Individuals to be involved in DNR policy development	Number of times mentioned by participants*
Parents	11
Administrators	10
Medical Consultant	8
Lawyers	8
School Nurses	7
Board of Education	7
Regular Education Teachers	6
Special Education Teachers	6
Special Services Division	4
Classified Staff	4
Registered Nurses	3
Religious Community Representative	3
Union Representatives from both Certificated and Classified Staff	3
Students	2
Counseling therapy	2
Representatives from Dept. of Health	2
Superintendent	1
"Specialist" from hospital	1
Representative for the Medically Fragile Child	1
Entire district needs to be involved	1
Committee with knowledge base	1
Someone who deals with ethics	1
Community members/anyone within the district who could be affected by the policy	1
Experts in the field	1
EMT or paramedics	1

*Numbers may reflect multiple responses from individual participants.

Question Six

Participant #11 stated that this was the most difficult of all the questions of the interview. "No one in the district would want to initiate policy unless there

is a need for such a policy. If the need isn't there, there is no need to develop a policy. If there is a context for the need then the policy would be developed. It is tough to make a proactive stance of such an issue, it's more of a reactive stance, within the context of meeting the child's needs." The responses to this question fell into one of either two responses. Participants either saw policy development beginning with the Board of Education and going "down" the chain of command or participants saw beginning policy development as a grass roots type of effort that ended up at the doorstep of the Board of Education.

Grass Roots Policy Development. Most of the participants saw beginning policy development starting with a small group of "experts," a committee, who draft a policy after plenty of time for discussion, a needs assessment, legal consultation and consultation with other districts that have policies. Interested parties and/or stakeholders would review the draft policy and a recommendation would be made to the Board of Education. Eight participants saw policy development occurring in this way.

Impetus of the Board of Education. Four participants mentioned a policy coming as an impetus of the Board of

Education. Participant #14 said, "From Board approval, back through the district, administrators, teachers and then the info to the parents." "Board consulted first to make sure" (from participant #9) and "There are district guidelines for Board policies" (from participant #12) are additional statements that represent this view of policy development.

Either/Or. Participant #4 made a statement about the process being public or private, "It can go either way: the Board can be informed publicly during a Board meeting that there is a need for policy and indicate to them the process-administrators need to develop a policy-or the need for policy can be a closed discussion. Something this explosive and controversial you want the Board on board."

Many of the participants who saw beginning policy development starting in committee did articulate that ultimately a draft policy has to be approved by the Board of Education and the district Superintendent.

Table 7. Question Six

Process of beginning DNR policy development	Number of times mentioned by participants
Grass roots policy development; "bottom-up"	10
Board of Education initiative; "top-down"	4
Either/Or	1

Question Seven

There were two main response themes to this question.

Widespread Training. Eleven of the participants thought a widespread training or dissemination of information was needed to introduce a DNR order policy within the local school district. "Probably do a staff training, one or two of the individuals who were involved with the policy development could go to school sites," was the response of participant #13. Participant #11 said, "Give the policy to the administration team, explain the context and why, explain to the unions and then immediately reassure staff as to their responsibility and liability in the situation." "First the policy goes to the administration council, all the management team, which is the regular way any policy should be introduced within the district. Then site staff usually look at the policy by themselves," said participant #2. And participant #10 responded, "Hopefully it would have been announced in the media that DNR orders were first going to be explored by the district." Within the group of participants that believe a wide dissemination of policy information was needed are participants that also made statements regarding sharing only part of the policy with staff. Participant #9 stated, "Putting aside or excluding the

fact that people would be livid and upset, then, the policy would be distributed as anything is throughout the district: by training at sites where people request actual training, that is, where there is a DNR request by parents." "The policy would be given out as general information. There's not a lot of impact unless you have a student at your school who may need to have a DNR," added participant #15. Participant #1 believed the policy should be introduced, "released," simultaneously to the school district and the community: "It would be released in three ways: a letter from each site to families, a press release within local newspapers and found in the records of Board meetings."

Need to Know Basis. The other response theme to this question can be summed up by the phrase "need to know basis." Three participants mentioned that particular phrase when discussing how they believed a DNR policy should be introduced within the school district community. "As needed thing" (participant #8), "need to know; as needed basis" (participant #6) and participant #4 states, "This is not one of those policies that goes to staff meetings. It would be addressed as the need arises."

Would not Introduce. Finally, one participant would not introduce the policy because this participant does not

believe DNR orders should be allowed in the school setting.

Table 8. Question Seven

How is a DNR policy to be introduced within the school district	Number of times mentioned by participants
Widespread dissemination	11
Need to know basis	3
Not introduced at all	1

Question Eight

There are primarily two points of view expressed in response to the question.

Inform the Community. There are those participants, such as participant # 3, who believed "You involve the community in developing because it's a hot topic. You could have evening discussions session." Participant #11 believed that "you work through the employees. If the Board approves and then the PTA council, parent groups, constituents, local medical groups are available, lots of information where it is critical to have it." Nine participants agreed with the thorough information position. "There is a real need to be invitational with the community because this is a highly sensitive and philosophical issue," said participant #1. Participant #2 said, "There needs to be community input, newspaper and

media need to be involved regarding the policy. The policy needs to go home at the first of the year along with other major policies for review." And participant #5 responded, "Go to key opinion leaders in positioned places of power-CEO of a hospital, for example-to garner responses."

Do not Inform the Community. Six participants believed as did participant #7, "I wouldn't introduce it because I don't believe there should be a policy. Why would we have to introduce it? A DNR is an individual request by parents. If it needs to be implemented we would answer questions from the community only as 'we are following board policy'." Participant #4 responded, "If the Board adopted the policy I don't see the need to introduce it to the community. The policy is made public, by public record, in the Board meeting minutes."

Participant #13 continued, "My first inclination with a policy that could effect a whole student body would be to send it home in a letter to parents, but I don't think you'd want to do that with this one." "Don't advertise, don't make an announcement. It doesn't work that way. Just put a line or blurb in the parent handbook regarding, 'If you have need for a DNR order at school, contact the school'," adds participant #9. Participant #15 stated, "You're probably not going to have a Do Not Resuscitate

night at school. Honestly, I can't see doing a lot of education with the community about it."

Table 9. Question Eight

How is a DNR policy to be introduced to the local community	Number of times mentioned by participants
Inform the community	9
Do not inform the community	6

Question Nine

Adhere to State and Federal Law. Eleven participants said they would have to, along with participant #4, "adhere to state and federal law. It plays a major role in what we do and what policy says." Participant #11 went on to say, "The law dictates your decision. If there is a valid and compelling reason for the policy people will understand unless they don't want to." Participant #13 said, "If something came down from the state saying we'd have to develop policy, we'd have to develop policy." "Sure, I'm sure we would follow the law," stated participant #12 and "Whatever it says we'll do the district would make the policy," from participant #8. Participant #9 said that if there were state and federal laws regarding DNR policy that "it changes everything. It takes the onus off the opinion of the person generating the policy. If the law developed that each district had to

develop policy, pro or con, it would be more difficult than if the law stated districts had to allow for a DNR order request."

The statements continued, "If you have a law you have to comply, most policies come through because of laws. Laws are the driving force to make it happen, it makes it easier for school districts to follow," said participant #3. And, "Clearly if there are laws prohibiting, enabling, mandating, we would follow the law. Is the policy we instituted consistent with federal and state laws?" from participant #6. Participant #10 stated that this is a tough question and would depend on the situation. "If I was unhappy with the decision I wouldn't work there but if I had to follow a law I would."

Question State and Federal Law. Three participants articulated that state and federal laws would not impact them at all. Participant #2 stated, "I would go to jail if I had to choose between the law and helping a child in need. An instinct would kick in, I could always say I forgot they had a DNR order." "For someone in the state to make a statement or law is arrogant. If the feds did it, it would be worse. It would be better if they recommended policy development. If it came from them I probably would run in the opposite direction," responded participant #14.

Participant #5 said that laws are both complimentary and contrary to the issue. This participant personally would not feel comfortable breaking the law but there would also be a personal dimension for this participant. "I would want to honor a personal decision of the family to have a DNR but I don't want to break the law of the land. Depending on the law it could impact either way."

Lack of Knowledge. One participant thought the question was asking if they knew what the state and federal law was regarding DNR policies. This participant would not develop policy.

Table 10. Question Nine

Impact of state and federal laws on decision to implement DNR policy	Number of times mentioned by participants
Would adhere to state and federal laws	11
Would question state and federal laws	3
Lack of knowledge to answer question	1

Question Ten

As answers to questions were tabulated a pattern, or certain language, emerged that confused the investigator. One of the first participants raised a question about whether the investigation was concerned with DNR orders or was the investigation concerned with DNR policy. The participant stated that the two could be dealt with

separately and did not believe that a DNR policy is needed in the school setting: policy is a serious issue that is usually the result of court action. This participant stated that a DNR order could be dealt with as any other issue that is brought before the IEP team and as the result of parental intent. The participant did not see a problem with accepting a DNR order from a parent without a DNR policy in place in the school district. Then, participant #4 was "shocked to find out that parents could write DNR orders for their children." One participant thought the family simply needed to note on the school emergency card that the family had chosen a DNR for their child. Another participant said that there would be questions about the family's right to make a DNR determination for the child.

These statements were interspersed throughout all the responses to the questions. In addition to this type of statement the investigator was surprised by the intensity of some of the respondents to questions regarding administrators having the right training to make a judgment about DNR orders. Some participants demonstrated heightened concern, as participant #2, "Administrators are not medically prepared to make this decision; an order would be a subjective decision." "It would be difficult to

follow a DNR if one thought another medical intervention could assist a life," stated participant #6. And, participant #1 responded, "District employees are not trained to determine if a situation is truly life or death."

Close to the end of the interview process an additional question was formulated after much of the data had been reviewed and the investigators' own assumptions had been clarified. This last question was asked of the last participant, participant #15. The participant was asked if they knew where a DNR order came from. The answer was, "No, I assume a parent." When it was explained to the participant that a DNR order came from one or two physicians and by patient consent the participant said, "Pass that along to those in the know."

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

This study interviewed 15 administrators from one school district in Southern California to explore their attitudes and beliefs about DNR orders in the school setting for terminally ill and medically fragile students. The school district in which the interviews took place currently serves such children as required by IDEA and does not have policy regarding DNR orders in the school setting. Three themes emerged from the study: (a) lack of administrator knowledge about DNR orders; (b) administrator fear and anxiety related to their role with respect to DNR order/policy; and, (c) emotional aspects or reactions of others at school site to a child death.

Administrator Attitudes

The majority of administrators interviewed did not want to see DNR orders in the school setting. This opinion, as the data shows, is because such a situation is seen as being too emotional for staff and too much of a burden on staff, and because administrative and school staff believe they are not trained to make a determination about life and death. The few participants who believed

DNR orders are consistent with school care of the medically fragile student are individuals who have articulated, for various reasons, that they have thought more about death. However, these participants still state that they know how difficult the situation could be for most administrators and educators to accept.

The data shows that DNR orders are such "a hot topic," as participant #3 said, that four of the 15 participants would not introduce DNR policy within the school district and six of the 15 participants would not introduce DNR policy to the community.

Impact of Data on School Nursing Practice

The results of the study are significant for school nursing and for the medically fragile student. The results demonstrate strong feelings on the part of a majority of participants about not having DNR orders in the school setting. Participants state that having DNR orders in the school setting is too emotional and say that they, as non-health related professionals, are not trained or equipped to handle a DNR order in the school setting. Participants state that the ethical dilemma involved, the emotions involved and the lack of training are all barriers to the development of DNR policy. This strong

reaction to the possibility of having a student in the school setting who may not receive CPR makes the prospect of initiating DNR policy development difficult. The efforts of the school nurse, as the bridge person between the school district and the health care community, and on behalf of the medically fragile student, would have to begin with an understanding of the anxiety administrative staff have related to this issue. The school nurse would need to approach the topic with sensitivity and much information in order to assist the school district in a process of change towards DNR policy development. The needs of the medically fragile student may not be met as easily or as quickly desired due to reaction toward the issue.

Very few participants are in support of DNR policy development or are resigned to the eventuality of DNR policy development. These individuals would be helpful to include in the process of beginning DNR policy development, as advocates for the medically fragile student and for the process.

Participants expressed limited and partial understanding of DNR orders. Lack of knowledge regarding the DNR decision is evident by administrator statements that they would want to attempt CPR because "I would feel

like I just would never know; did we do everything we could?" (participant #8), "It would be difficult to follow DNR if one thought another medical intervention could assist a life" (participant #6) and "Not to perform duties that would save a life? I wouldn't do it" (participant #4).

The understanding that CPR will not save the life of student with a DNR order is what is lacking. School nurses, when initiating discussion about DNR orders in the school setting, would need to begin the process by providing thorough education about DNR orders for key administrative staff so they would better understand what a DNR order is, why it is implemented and how important it is for the medically fragile student and the student's family.

Participants who understand the DNR order are good resources for DNR policy initiation. Most of the few participants who fully understood the DNR process made up those individuals who support DNR policy development.

Participants were quite clear when saying that the biggest advantage to having a DNR policy would be that the process of following a DNR order in the school setting is then clearly stated. Individual responsibility would be outlined and the possibility of surprise minimized. Also,

participants acknowledged that DNR policy development would meet the needs of the parents whose child had a DNR order. This knowledge could be a starting point in discussing whether or not DNR policy will be developed. Knowing that administrators feel more confident regarding what decisions to make if there is a clearly stated policy is one way to make initial discussion more palatable. In addition, administrators would welcome information regarding another way they could meet parent needs. It will be helpful to offer administrators tools with which they can encounter the potentially emotional situation of a DNR order. Since about a third of the participants feel there is no advantage to having DNR policy in the school setting, despite the fact that it clarifies the process for staff, it is important for the school nurse to recognize this response when attempting to initiate policy development.

Parent needs are also high on the list when it comes to participant initial policy development. As participants feel it is most important to have parents be part of policy development, along with administrators, a medical consultant and lawyers, then it would be important for the school nurse to utilize this information when a committee needs to be formed to address DNR policy for the school

district. It is interesting to note that representatives from these same groups are also mentioned in the literature regarding individuals to involve in policy development. The school nurse would certainly support a wide representation of professionals developing policy on behalf of the medically fragile student.

In addition to parents, administrators, medical consultants and lawyers, participants suggested a wide variety of professionals who could or should be present in a committee designated for DNR policy development. This multi-profession represented group is consistent to how most participants responded about how to begin policy development; by a "grass-roots" effort, a committee developed draft of DNR policy that is then presented to the Board of Education. Most participants feel that policy development should begin this way, or, understand policy development as beginning this way. A few participants believe that DNR policy impetus should come from the Board of Education or district Superintendent "down" to a committee. All participants understand that eventually any policy has to be approved by the Board of Education prior to implementation. It is important for the school nurse to understand the process of policy development within the school district.

Data Results Related to the Literature

The results of this study are consistent with the literature related to the study. Most school districts do not have a policy that addresses DNR orders in the school setting. The school district represented in this study does not have a DNR policy. There is inconsistency throughout the country regarding statutes related to DNR orders in the community setting. This inconsistency and confusion of information impacts the knowledge of school district administrators about how a DNR order is obtained for a student. Participant understanding of who could be involved in procedure development and implementation is also supported by the literature, many sources delineating the same professionals to be involved in procedure implementation as were detailed by the participants.

The data from this study supports a recommendation in the literature that school district administrator attitudes and knowledge be researched, the data then gathered to assist the school nurse in encouraging and initiating DNR policy in the school setting.

Limitations of the Study

This study occurred in one school district in Southern California, limiting its generalizability to

other school districts. This study questioned 15 of 64 administrators within this school district. It cannot be known if these 15 are representative of all administrators in the school district. The study does not examine staff members regarding their attitudes towards DNR orders in the school setting. Interviewing all administrators within the district would add another dimension to the examination of DNR orders in the school setting as would assessing the attitudes of teachers and classified staff about DNR orders.

Repeating the study in another year, repeating the study with a larger group of administrators or all administrators in this school district is a suggestion for future research. Repeating the study in other school districts is also a suggestion for additional research. Repeating the study after a parent has petitioned the school district to accept a DNR order on behalf of their child or after a terminally ill student dies in school setting would also provide more information in the future.

Reflections and Recommendations

DNR orders in the school setting will never be, gratefully, a large part of school district functioning, but they may be an infrequent necessity for a few

medically fragile students. If school districts are required by law to serve the medically fragile student then DNR orders are the logical extension of care for some of these students. DNR policy development is morally right on behalf of the medically fragile student who requires a DNR order. The policy to allow for DNR orders in the school setting may be the final way a district serves that medically fragile student. The school district supports the family and the family's decision by crafting DNR policy. Developing DNR policy proactively, not as a result of litigation, would be wise, as policy would be in place when such a policy is required. Not only would DNR policy development be wise in terms of preparedness on the part of the school district, policy development would lead to procedural guidelines. Procedural guidelines exist to clarify for staff what to do for the medically fragile student with a DNR order and would decrease stress and anxiety related to working with this type of student and their family.

It is in the best interests of the school district to promote openness towards and a dialogue about this possible final need of the medically fragile student.

APPENDIX A
INTERVIEW SCHEDULE

QUESTIONS FOR INTERVIEW

1. What are your personal feelings related to having Do Not Resuscitate orders in the school setting?
2. What do you see as advantages to developing a Do Not Resuscitate order in the school setting?
3. What do you see as barriers to the development of a Do Not Resuscitate order in the school setting?
4. Which individuals do you think should be part of the process of developing a Do Not Resuscitate policy?
5. What should be the process of beginning policy development?
6. How do you see a Do Not Resuscitate policy being introduced within the school district community?
7. How do you see a Do Not Resuscitate policy being introduced to the local community?
8. How would federal and state laws regarding Do Not Resuscitate orders in the school setting impact your decision to institute Do Not Resuscitate policy development?

APPENDIX B

INFORMED CONSENT FORM



**CALIFORNIA STATE UNIVERSITY
SAN BERNARDINO**

5500 University Parkway, San Bernardino, CA 92407-2397

COLLEGE OF NATURAL SCIENCES

Department of Nursing

(909) 880-5380

fax: (909) 880-7089

INFORMED CONSENT

The study in which you are being asked to participate is designed to investigate attitudes towards the development of a Do Not Resuscitate policy in the K-12 school setting. This study is being conducted as a graduate thesis by Martha Hone-Warren under the supervision of Dr. Ellen Daroszewski, Professor of Nursing. This study has been approved by the Institutional Review Board, California State University, San Bernardino.

In this study you will be given a list of questions that will provide an opportunity to explore attitudes related to the development of a Do Not Resuscitate policy in the K-12 school setting. At the same time the questions are given to you an appointment will be made for an interview with Martha Hone-Warren. The interview will provide an opportunity for further discussion and clarification of responses to the questions. The interview should take from one to two hours to complete. All of your responses will be held in the strictest of confidence. Your name will not be reported with your responses. All results will be reported in group form only. You may receive the group results of this study upon completion of Spring Quarter 2004, July 1, 2004, by contacting Martha Hone-Warren at martha.hw@verizon.net and at 909-798-3071.

Your participation in this study is totally voluntary. You are free not to answer any questions and withdraw at any time during this study without penalty. If, at any time, this study causes you distress and you need to speak with someone about it, you will be referred to your personal benefit-provided mental health advisor. In order to assure the validity of this study, we ask that you not discuss this study with others.

If you have any questions or concerns about this study, please feel free to contact Dr. Ellen Daroszewski at 909-880-7238.

By placing a check mark on the line below, I acknowledge that I have been informed of, and that I understand the nature and purpose of this study, and I freely consent to participate. I also acknowledge that I am at least 18 years of age.

Place a check mark here _____ Today's date _____

The California State University

*Bakersfield • Channel Islands • Chico • Dominguez Hills • Fresno • Fullerton • Hayward • Humboldt • Long Beach • Los Angeles • Maritime Academy
Monterey Bay • Northridge • Pomona • Sacramento • San Bernardino • San Diego • San Francisco • San Jose • San Luis Obispo • San Marcos • Sonoma • Stanislaus*

APPENDIX C
CALIFORNIA STATE UNIVERSITY SAN BERNARDINO
INSTITUTIONAL REVIEW BOARD
APPROVAL LETTER



**CALIFORNIA STATE UNIVERSITY
SAN BERNARDINO**

5500 University Parkway, San Bernardino, CA 92407-2397

12/05/2003

Ms. Martha Hone-Warren
c/o: Prof. Ellen Daroszewski
Department of Nursing
California State University
5500 University Parkway
San Bernardino, California 92407

**CSUSB
INSTITUTIONAL
REVIEW BOARD**

Exempt Review

IRB# 03038

Status

APPROVED

Dear Ms. Hone-Warren:

Your application to use human subjects, titled, "Exploration of School Administrator Attitudes Regarding Implementation of Do Not Resuscitate Policy in the Elementary and Secondary School Setting" has been reviewed and approved by the Institutional Review Board (IRB) of California State University, San Bernardino

You are required to notify the IRB if any substantive changes are made in your research prospectus/protocol, if any unanticipated adverse events are experienced by subjects during your research, and when your project has ended. If your project lasts longer than one year, you (the investigator/researcher) are required to notify the IRB by email or correspondence of *Notice of Project Ending* or *Request for Continuation* at the end of each year. Failure to notify the IRB of the above may result in disciplinary action. You are required to keep copies of the informed consent forms and data for at least three years.

If you have any questions regarding the IRB decision, please contact Michael Gillespie, IRB Secretary. Mr. Gillespie can be reached by phone at (909) 880-5027, by fax at (909) 880-7028, or by email at mgillesp@csusb.edu. Please include your application identification number (above) in all correspondence.

Best of luck with your research.

Sincerely,

Joseph Lovett, Chair
Institutional Review Board

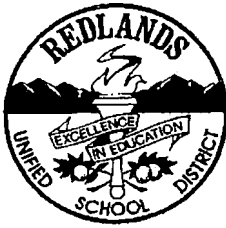
JL/mg

cc: Prof. Ellen Daroszewski, Department of Nursing

The California State University
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Monterey Bay • Northridge • Pomona • Sacramento • San Bernardino • San Diego • San Francisco • San Jose • San Luis Obispo • San Marcos • Sonoma • Stanislaus

APPENDIX D

LOCAL SCHOOL DISTRICT PERMISSION TO STUDY LETTER



REDLANDS UNIFIED SCHOOL DISTRICT

Board of Education

Pat Kohlmeier
Ron McPeck
Barbara Phelps
Donna West
Neal Waner

Superintendent

Robert J. Hodges

November 13, 2003

To Whom It May Concern:

This letter grants Martha Hone-Warren, RN, District Nurse, permission to survey administrative staff, employed by Redlands Unified School District, for the purpose of her Master's thesis in nursing study. I understand the study is supervised by Dr. Ellen Daroszewski, Professor in the Department of Nursing at California State University, San Bernardino.

I have been assured the information will be used for the sole purpose of investigating administrative concerns related to the development of a *Do No Resuscitate* order in a school setting. I also understand the information will remain confidential.

Sincerely,

Robert J. Hodges
Superintendent of Schools

RJH2/ck/Master Thesis

20 West Lugonia Avenue • P.O. Box 3008 • Redlands, California 92373-1508
(909) 748-6712 • Fax (909) 307-5312

APPENDIX E

HUMAN PARTICIPANT PROTECTIONS EDUCATION FOR

RESEARCH TEAMS CERTIFICATE



Human Participant Protections Education for Research 1

Completion Certificate

This is to certify that

Martha Hone-Warren

has completed the **Human Participants Protection Education for Research Teams** online course, sponsored by the National Institutes of Health (NIH), on 04/25/2003.

This course included the following:

- key historical events and current issues that impact guidelines and legislation on human participant protection in research.
- ethical principles and guidelines that should assist in resolving the ethical issues inherent in the conduct of research with human participants.
- the use of key ethical principles and federal regulations to protect human participants at various stages in the research process.
- a description of guidelines for the protection of special populations in research.
- a definition of informed consent and components necessary for a valid consent.
- a description of the role of the IRB in the research process.
- the roles, responsibilities, and interactions of federal agencies, institutions, and researchers in conducting research with human participants.

National Institutes of Health
<http://www.nih.gov>

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