

▷ Masters Research Project

Life Support Decisions Involving Imperiled Infants:

An NRSA Grant Application

Lucia D. Wocial

Oregon Health Sciences University

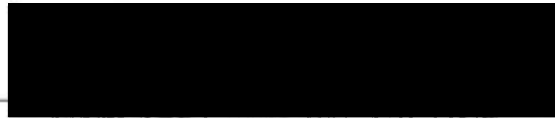
School of Nursing

Department of Family Nursing

APPROVED



Virginia P. Tilden, RN, DNSc, FAAN
Professor, Research Advisor



Mary Ann Curry, RN, NP, DNSc
Professor, Committee Member



Sheila Kodadek, RN, PhD
Associate Professor, Department Chair, Family Nursing

Life Support Decisions Involving Imperiled Infants:
An NRSA Grant Application

A National Research Service Award (NRSA) grant application was the project submitted to fulfill the requirements for the Masters Research Project (MRP) as part of my Master of Science in Nursing degree. The grant application was submitted to the National Institutes of Health (NIH) for the September 10, 1992 deadline. I chose this project because I plan to continue my graduate work and pursue a doctoral degree in nursing from the Oregon Health Sciences University (OHSU). If approved, the grant would provide financial assistance for completion of the research I plan to pursue as part of my doctoral dissertation.

Congress created NRSAs in 1974 in order to ensure a superior national program of research into physical and mental diseases and impairments of man. The grants were designed to provide financial support to researchers and their sponsoring institutions.

Candidates who plan to conduct research in areas of nursing apply to the National Center for Nursing Research (NCNR) through the Department of Health & Human Services, part of the Public Health Service. Predoctoral researchers apply at one of three levels. At level one, candidates have not fully started course work at the doctoral level or have not yet completed the first quarter/semester of the doctoral program. Candidates at level have taken some course work at the doctoral level but have not yet completed candidacy examinations or

have not had their proposal approved by their dissertation committee. Candidates at the third level have completed all of their course work.

Recipients of NRSA grant awards are expected to conduct research within two years of termination of the award and continue to do research in their chosen field for a period equal to the length of the NRSA award.

This NRSA grant application was submitted for level one consideration. At this level, review criteria is based on the most recent academic performance, past experiences, references supportive of a research career, and evidence of scholarship and analytical ability. Applications are reviewed for scientific merit and training potential of the applicant.

Applications should include an adequate description of a problem area in which a proposal can be developed and several potential research questions. The literature review should include interpretation and identification of the critical concepts related to the problem area.

On November 16, 1992 the application received a priority rating of 117. The remainder of this Masters Research Project is a copy of the NRSA grant application, as submitted to NIH on September 10, 1992.

DEPARTMENT OF HEALTH AND HUMAN SERVICES PUBLIC HEALTH SERVICE INDIVIDUAL NATIONAL RESEARCH SERVICE AWARD APPLICATION <i>Follow instructions carefully. Type in the unshaded areas only.</i>		LEAVE BLANK		
		TYPE	ACTIVITY	NUMBER
		REVIEW GROUP		FORMERLY
		MEETING DATES		DATE RECEIVED
1. TITLE OF RESEARCH TRAINING PROPOSAL <i>Do not exceed 56 typewriter spaces</i> Life Support Decisions Involving Imperiled Infants				
2. LEVEL OF FELLOWSHIP Predoctoral		3. PROGRAM ANNOUNCEMENT AREA Nursing Research (NR)		
4a. NAME OF APPLICANT <i>(Last, first, middle initial)</i> Wocial, Lucia D.		4b. HIGHEST DEGREE(S) MS as of 12/92	4c. SOC. SEC. NO. 541-86-9230	
4d. PRESENT MAILING ADDRESS <i>(Street, city, state, zip code)</i> 11410 SW 47th Avenue Portland, OR 97219-7348		4e. PERMANENT MAILING ADDRESS <i>(Street, city, state, zip code)</i> same as 4d		
4f. OFFICE TELEPHONE NO. <i>(Area code, no., and ext.)</i>		4g. HOME TELEPHONE NO. <i>(Area code and no.)</i> 503/452-1644	4h. PERMANENT TELEPHONE NO. <i>(Area code and no.)</i>	
4i. <input checked="" type="checkbox"/> U.S. CITIZEN OR U.S. NONCITIZEN NATIONAL OR <input type="checkbox"/> PERMANENT RESIDENT OF U.S. (NOTARIZED STATEMENT REQUIRED)				
5. TRAINING UNDER PROPOSED AWARD <i>(See Lexicon)</i> DISCIPLINE SUBDISCIPLINE NO. NAME NO. NAME 410 Nursing 993 Bioethics		6. DELINQUENT FEDERAL DEBT <input checked="" type="checkbox"/> NO <input type="checkbox"/> YES If "Yes," attach an explanation to the CHECKLIST page.		
7a. DATES OF PROPOSED AWARD FROM (YYMMDD) THROUGH (YYMMDD) 930301 960630		7b. PROPOSED AWARD DURATION YEARS MONTHS 3 4	8. DEGREE SOUGHT DURING PROPOSED AWARD DEGREE EXPECTED COMPLETION DATE PhD June 1996	
9. HUMAN SUBJECTS 9a. <input type="checkbox"/> NO <input checked="" type="checkbox"/> YES IF YES, EXEMPTION NO. OR IPB APPROVAL DATE indefinite		9b. ASSURANCE OF COMPLIANCE NO. M1359-01	10. VERTEBRATE ANIMALS 10a. <input type="checkbox"/> NO <input checked="" type="checkbox"/> YES IF YES, IACUC APPROVAL DATE	
11a. NAME OF SPONSOR <i>(Last, first, middle initial)</i> Tilden, Virginia P. OFFICE TELEPHONE NO. <i>(Area code, no. and ext.)</i> (503) 494-3857		11b. PROPOSED SPONSORING INSTITUTION NAME Oregon Health Sciences University ADDRESS <i>(Street, city, state, and zip code)</i> 3181 SW Sam Jackson Park Road Portland, Oregon 97201-3098		
11c. DEPARTMENT, SERVICE, LABORATORY, OR EQUIVALENT Family Nursing				
11d. MAJOR SUBDIVISION School of Nursing		12. ENTITY IDENTIFICATION NO. 1936001786B8		
13. NAME AND ADDRESS OF INSTITUTION WHERE TRAINING WILL TAKE PLACE, IF DIFFERENT FROM ITEM 11b. NAME AND TELEPHONE NO. OF ADVISOR IF DIFFERENT FROM 11a. Mark Merkens, MD (co-sponsor) (503) 494-6527		14. NAME OF OFFICIAL IN BUSINESS OFFICE Dennis Borden, PhD TELEPHONE <i>(Area code, no. and ext.)</i> (503) 494-7784 TITLE Asst. Vice Pres., Res. Admin. ADDRESS Oregon Health Sciences Univ. 3181 SW Sam Jackson Park Road Portland, Oregon 97201-3098		
15. APPLICANT CERTIFICATION AND ACCEPTANCE: I certify that the statements herein are true and complete to the best of my knowledge. I certify that I have read the National Research Service Award Service Assurance, and will abide by the Assurance if an award is made, and that the award will not support residency training. I further certify that I will comply with applicable Public Health Service terms and conditions in effect at the time of the award. A willfully false certificate is a criminal offense (U.S. Code Title 18 Section 1001).				
SIGNATURE <i>(Required of each applicant)</i> Lucia D Wocial			DATE Sept 09, 1992	

INDIVIDUAL NRSA APPLICATION-CONTINUED

(To be completed by applicant—follow instruction sheet)

NAME (Last, first, middle initial)

Wocial, Lucia D.

16a. APPLICANT'S EDUCATION

DEGREE	DATE	FIELD	INSTITUTION	MENTOR
BA	May 1982	Psychology	Macalester College	N/A
BS	June 1985	Nursing	Oregon Health Sciences University	N/A
MS	December 1992	Nursing	Oregon Health Sciences University	Dr. Virginia Tilden

16b. APPLICANT'S NON-DEGREE TRAINING

ACTIVITY	BEGINNING DATE	ENDING DATE	FIELD	INSTITUTION	SUPERVISOR
Certification for advanced practice (See Continuation page 2.1)	12/89	renewed 12/91	Neonatal Intensive Care Nursing	NAACOGN Certification Corporation	

17. TITLE(S) OF THESES/DISSERTATIONS

Honor's Thesis, Macalester College, 1982: *The Role of Sensory-Motor Stimulation in the Development of Preterm Infants*
 Master's Research Project, OHSU, 1992: *Experiences of Families of Withdrawing/Withholding Treatment from Imperiled Infants: Literature Review & Proposal Development.*

18. OTHER RESEARCH AND PROFESSIONAL EXPERIENCE

Summer Medical Research Internship, 1981, awarded to students interested in pursuing a medical/research career. Sponsored by Macalester College and the University of Minnesota.
 Research Assistant Microbiology Research Lab, 1982-1985.

19. GOALS FOR FELLOWSHIP TRAINING AND CAREER

My immediate goal is to complete the doctoral program in nursing (Appendix A), with a minor in health care ethics, at the Oregon Health Sciences University (OHSU) School of Nursing. I wish to improve my skills in evaluating current research and theory and to develop expertise in conducting research to build and test theories relevant to nursing. My long-term goals are to teach at the university level, to create staff development programs that increase knowledge of nurses in clinical practice, and to pursue research relating to families who are faced with ethical dilemmas regarding their infants and children, with the goal of developing practical intervention strategies nurses can use to help families cope with the stress of these situations.

20a. NAME AND DEGREE(S):

Virginia P. Tilden, DNSc, FAAN

Co-sponsor: Mark Merckens, M.D.

20b. POSITION/RANK:

Professor & Assoc. Dean for Research

Staff Attending Physician, Adjunct Assoc.

20c. RESEARCH INTERESTS/AREAS:

Professor

family ethical decision making; nursing ethics; family stress and coping; measurement; social support; family violence

21. DESCRIPTION

The proposed area of dissertation study within this research training program will focus on the experiences of families in the Neonatal Intensive Care Unit (NICU) who are faced with the dilemma of withholding and/or withdrawing treatment from their infants. Although parents must live with the outcome of the decision to withdraw or withhold treatment from their infant, there is little empirical information about what parents experience when their infant is the center of an ethical dilemma in the NICU. The general aims of the proposed dissertation research are to: 1) describe parents' experiences with ethical decision making in the NICU; 2) explore NICU nurses' knowledge and experiences in caring for imperiled infants and their families; 3) generate knowledge that will guide NICU nurses in their care of imperiled infants and their families; and 4) describe intervention strategies that families identify as helpful in improving their ability to cope with the stresses of facing an ethical dilemma in the NICU. The long-term goal of the proposed study is to develop nursing intervention strategies that will promote family well-being during the crisis of ethical decision making. Because there is limited nursing knowledge in this area, qualitative research methods offer the most potential for generating rich descriptions of these phenomena. Interviews, document reviews and participant observation are all potential methods to be used in data production. Analysis of data will focus on describing parents' experiences with the events surrounding the discussion of withholding and/or withdrawing treatment from their infant. The goal is to identify concepts and processes, and their linkage. The long-term goal of a program of research on this topic is hypothesis generation and testing.

INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D

APPLICANT'S NON-DEGREE TRAINING

Activity	Dates	Field	Institution	Supervisor
Neonatal Adv. Life Support	12/89 renewed 3/92	Neonatal Nursing	American Academy of Pediatrics/ American Heart Association	
Summer Seminar in Health Care Ethics			University of Washington	Albert Jonsen, Principal Faculty

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INDIVIDUAL NRSA APPLICATION—CONTINUED

NAME OF APPLICANT (*Last, first, middle initial*)

TABLE OF CONTENTS

Type the name of the applicant at the top of each printed page and each continuation page.

Wocial, Lucia D.

Page Numbers
(Number pages consecutively at the bottom throughout the application. Do not use suffixes such as 5a, 5b.)

SECTION 1—Applicant

Face Page (Items 1-8), Page 2, (Items 16-19, 21), and Table of Contents.....	1-3
Scholastic Performance.....	4-5
Background.....	6
Research Experience	
a. Summary.....	7
b. Doctoral Dissertation.....	7
c. Publications.....	7
Revised Application.....	7
Research/Training Plan.....	8-18
a. Activities Under Award.....	8
b. Research Proposal.....	8-18
(1) Specific Aims.....	8-9
(2) Background Significance.....	9-12
(3) Experimental Design and Method... } (Not to exceed 10 pages.).....	12-15
(4) Literature.....	15-17
(5) Human Subjects/Vertebrate Animals.....	17
c. Respective Contributions.....	17
d. Selection of Sponsor and Institution.....	17-18

SECTION 2—SPONSOR

Biographical Sketch.....	19-20;22-23
Research and Training Support/Previous Trainees.....	21
Facilities and Commitment Statement.....	24-32
Training Plan, Environment, Research Facilities.....	24-31
Number of Fellows/Trainees to be Supervised.....	31
Applicant's Qualifications and Potential.....	32
Human Subjects.....	33
Vertebrate Animals.....	33
Hazardous Materials and Procedures.....	33

SECTION 3—Appendix

(3 collated sets. No page numbering necessary. Not to exceed 3 publications; 2 for predoctoral candidates.)

SECTION 4—References

(See instructions for submission of references)

Number of references included (*minimum 3*): 4

Other Items (list):

- Personal Data Page for fellows
- Checklist

INDIVIDUAL NRSA APPLICATION—CONTINUED

(To be completed by applicant—follow instruction sheet.)

NAME OF APPLICANT (Last, first, middle initial)

Wocial, Lucia D.

22. SCHOLASTIC PERFORMANCE: **Predoctoral applicants:** List by institution and year all undergraduate and graduate courses with grades. **Postdoctoral applicants:** List by institution and year all undergraduate courses and graduate scientific and/or professional courses germane to the training sought under this award with grades. Complete block at bottom of page, if applicable. **Senior applicants:** Omit this page.

SCIENCE			OTHER		
YEAR	COURSE TITLE	GRADE	YEAR	COURSE TITLE	GRADE
Macalester College			Macalester College		
<u>1979</u>	Principles of Biology	A	<u>1978</u>	Compulsion and choice	A
	Introduction to Zoology	B		Introduction to Statistics	B
	General Chemistry	B		Intro to Political Analysis	B
<u>1980</u>	General Chemistry	B		Introduction to German	B
	Neuroscience	B	<u>1979</u>	Analysis of Society	A
	Human Physiology	B		Developmental Psychology	A
	Organic Chemistry	B		American Civilization	A
<u>1981</u>	Organic Chemistry	B		Creative Writing	A
	Embryology	B		Educational Psychology	A
			<u>1980</u>	Philology	B
				Adult Development	A
				Psychological Studies	B
				Psychological Methods	B
			<u>1981</u>	Sex Roles and the Family	A
				Psychological Studies	A
				Psychological Methods	B
				Basic Financial Accounting	B
				Indep. Study (Honors Thesis)	A
				Internship (Family Plan Clin)	A
			<u>1982</u>	Computer Programming	B+
				Behavior Genetics	A-
				Indep. Study (Honors Thesis)	A
				Christians and Their Origins	S
Portland State University, Portland OR			Portland State University, Portland OR		
<u>1982</u>	Nutrition	B	<u>1983</u>	General Anthropology	A
			<u>1992</u>	Decision Making	A
Oregon Health Sciences University			Oregon Health Sciences University		
<u>1982</u>	Anatomy & Physiology	B	<u>1982</u>	Clinical Exp in Nursing	A
	Organic Chemistry	B		Clinical Exp in Nursing	B
	Nursing Science I	A		Clinical Exp in Nursing	B
<u>1983</u>	Nursing Science II	B		Maturing Family	C
	Microbiology	B		Family Nursing	B

Explain marking system if other than 1-100 or A, B, C, D, F. Show level required for passing. **Predoctoral applicants** state performance on Graduate Record Examination, if available.

Graduate Record Examination:

Verbal: 570 Quantitative: 680 Analytical: 710

INDIVIDUAL NRSA APPLICATION
 CONTINUATION PAGE
NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

Oregon Health Sciences University1983

Microbiology Lab	B
Nursing Science III	B
Pharmacology	C
Nursing Science V	C

1984

Nursing Science IV	B
Nursing Science VII	A

1985

Nursing Science VIII	B
Nursing Science IX	A

Oregon Health Sciences University1984

Emerging Family	A
Family Nursing	B
Childrearing Family	A
Family Nursing and the Child	A
Mental Health Nursing Clin	A
Mental Health Nursing Theory	B

1985

Acute Illness Clinical	A
Acute Illness Theory	B
Community Health Nsg Clinical	A
Community Health Nsg Theory	A

1991

Ethics and the Admin Role	A
Statistics	A
Nursing Context	A
Nsg Theory, Prac & Research	A
Family Process	A

1992

Measurement in Nursing	A
Strategies for Planned Change	A
Childrearing Family I	A
Research Design & Utilization	A
Families & Health Status	A
Childrearing Family II	A

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INDIVIDUAL NRSA APPLICATION—CONTINUED

(To be completed by applicant—follow instruction sheet.)

NAME OF APPLICANT (Last, first, middle initial)

Wocial, Lucia D.

23. EMPLOYMENT (after college) NAME AND LOCATION OF EMPLOYERS, INCLUDING MILITARY SERVICE	OCCUPATION OR POSITION TITLE	FROM		TO	
		Month	Year	Month	Year
U.S. Bancorp Portland OR	Proof Operator	June	1982	Sept	1982
Oregon Health Sciences University Dept of Microbiology, Portland OR	Lab Assistant	October	1982	Sept	1985
Children's Hospital National Medical Center, Washington, D.C.	Staff Nurse, Clinical Nurse II, NICU level II	Nov	1985	July	1989
Good Samaritan Hospital San Jose, CA	Staff Nurse, Clinical Nurse III, NICU level II & III	Aug	1989	June	1991
Favorite Nurses Portland OR	Temporary Nurse, NICU level II & III	July	1991	Present	
Oregon Health Sciences University University Hospital, Portland OR	Staff Nurse, NICU level II & III	June	1992	Present	

24. ACADEMIC AND PROFESSIONAL HONORS, including all scholarships, traineeships, fellowships, and development awards. Indicate source of awards (PHS, NSF, Woodrow Wilson, etc.), dates, and grant or award numbers. List current professional societies, if applicable.

HONORS

1978 National Merit Scholar Commended Student
 1978-1982 Dewitt Wallace Scholarship (Macalester College) awarded to National Merit Scholars
 1982 Graduated with Honors, Macalester College
 1985 Oregon Nurses' Association, Student Nurse Of The Year Award
 1992 Sigma Theta Tau, International Honor Society for Nursing, Oregon Health Sciences University,
 Beta Psi Chapter

Membership in Professional Organizations:

Oregon Nurses Association
 American Nurses Association
 National Association of Neonatal Nurses
 National Association of the American College of Obstetrics, Gynecology and Neonatology (NAACOGN)

25. NAME OF THESIS ADVISOR OR CHIEF OF SERVICE (If not sending this person a reference report, explain why.) Virginia P. Tilden, RN, DNS, FAAN	TITLE, DEPARTMENT, AND INSTITUTION Associate Dean for Research and Professor Office of Research Development and Utilization Oregon Health Sciences University School of Nursing
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26. APPLICATION FOR CONCURRENT SUPPORT NO YES

If "Yes," list all support (training, research, travel, etc.) applied for or for which an application is planned that would run concurrently with the period covered by this application. Include the type, source, amount, and dates.

INDIVIDUAL NRSA APPLICATION—CONTINUED

(To be completed by applicant—follow instruction sheet.)

NAME OF APPLICANT (Last, first, middle initial)

Wocial, Lucia D.

27. RESEARCH EXPERIENCE

- a. Summary
- b. Doctoral Dissertation
- c. Publications

28. REVISED APPLICATION

29. RESEARCH TRAINING PLAN

- a. Activities Under Award
- b. Research Proposal
- c. Respective Contributions
- d. Selection of Sponsor and Institution

27 Research Experience**a) Summary**

Summer Medical Research Internship. The purpose of this program was to allow undergraduate students interested in a research or medical career the opportunity to work with physicians in clinical practice and research. In my internship I worked with a neurologist. I gained knowledge in the clinical area of neurology, namely conduction of electromyography (EMG). I acquired knowledge and skills relevant to conducting animal research. I assisted with collection and analysis of data from experiments investigating diabetic neuropathy, using specially bred mice.

Honor's Thesis, Macalester College. This independent project primarily consisted of a literature review and synthesis of knowledge. The purpose of the review was to synthesize information in order to formulate appropriate research questions. The project included writing of the thesis and presentation of the information in a seminar format.

Research Assistant Microbiology Lab. I provided technical assistance for experiments with *Pseudomonas aeruginosa*. My work involved generation and analysis of data with laboratory and animal research experiments.

Master's Research Project. In this Master's Research Project, literature review and research proposal development were accomplished as a preliminary step to moving into the doctoral component of the graduate program.

b). Doctoral Dissertation - Not Applicable

c). Publications.

Wocial, L. (In Press). Advocacy in action. Neonatal Network.

28. Not Applicable

INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)**Wocial, Lucia D.****29 Research Training Plan****a) Activities Under Award**

<u>Academic Year</u>	<u>Activities</u>	<u>Percentage Time</u>
1993 (Spring)	Coursework	100%
1993-1994	Coursework Research	90% 10%
1994-1995	Coursework Research	80% 20%
1995-1996	Research	100%

Starting with Fall term, 1992 I will begin taking doctoral courses part-time while I complete my masters degree. I plan to complete my masters degree in December, 1992. Beginning with Winter term, 1993, I will be enrolled full-time in the doctoral program. I plan to take my comprehensive examinations, both oral and written, in the fall of 1994. I plan to defend my completed dissertation by June 30, 1996. Details of my coursework plans are provided in question #33.

b) Research Proposal**1) Specific Aims**

Studies that focus on family experiences with ethical decision making are underrepresented in the nursing literature (Chafey, 1992). The proposed area of study will focus on the experiences of families in the Neonatal Intensive Care Unit (NICU) who are faced with the dilemma of withholding and/or withdrawing treatment from their infants. Since the well publicized case of Baby Doe in 1982, debate and controversy have surrounded the care of imperiled infants in the NICU. Much of that debate has centered around treatment decisions physicians face. Experts (Fost, 1986; Kraybill, 1988; Pinch & Spielman, 1990) agree however, that parents will live with the outcomes of these decisions, yet there is little empirical information about what parents experience when their infant is the center of an ethical dilemma.

Nurses have the closest and most intense contact with families in the NICU. Nurses need research based knowledge to guide the care they provide to imperiled infants and families who face ethical dilemmas regarding life support for their infants. The few NICU nursing studies that already exist offer the beginnings of a practice based programmatic research effort in ethics (Chafey, 1992). More research in this area may lead to the development of practice generalizations for ethical dilemmas in neonatal nursing care that could be applied to other clinical settings. Therefore, the general aims of this proposed future dissertation research are to:

- 1) describe parents' experiences with ethical decision making in the NICU;
- 2) explore NICU nurses' knowledge and experience in caring for imperiled infants and their families;
- 3) generate knowledge that will guide NICU nurses in their care of imperiled infants and their families;
- 4) describe intervention strategies that families identify as helpful in improving their ability to cope with the stress of facing an ethical dilemma in the NICU.

Within these four general aims the following are specific potential research questions that may later be selected for dissertation study.

- 1) How do parents and health care professionals perceive the decision making process to withhold and/or withdraw treatment from an infant in the NICU?

INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

- 2) How does the uncertain prognosis of an infant influence parents' and health care professionals' feelings about pursuing treatment?
- 3) What roles do parents and health care professionals wish to play in the decision making process to withhold and/or withdraw treatment from an infant in the NICU and how does this compare with the roles they actually play?
- 4) What factors are most valuable in assessing parents' readiness and their ability to process information about their infants' condition and treatment options?
- 5) What intervention strategies would be most useful for promoting collaboration between families and health care professionals as they face dilemmas regarding treatment decisions in the NICU?

Ideally, parents collaborate with health care professionals to make treatment decisions for their infant. In a collaborative decision making process, parents bring the perspective of the infants' best interest while health care providers bring their clinical expertise (Fost, 1986). The close contact nurses have with families and the intense care they provide to infants gives them special knowledge relevant to treatment decisions and helps them facilitate parental involvement in ethical decision making. Developing nursing intervention strategies that will promote family well-being during the crisis of ethical decision making in the NICU is the long-term goal of the proposed area of study. Information from this study will provide NICU nurses with tools to help them prepare parents for, and cope with, the crisis of an ethical decision.

2) Background Significance

Three significant developments in the past 25 years have shaped the course of neonatal care in the United States : 1) rapid increase in the number of NICUs, 2) rapid development of medical technology, and 3) the Baby Doe Regulations. In 1965 only 16 NICUs were operating in the U.S. (Pinch & Spielman, 1989). By 1988, 650 and by 1991, a total of 12,384 beds in 737 NICUs existed in the U.S. (American Hospital Association, 1992). In 1990, 7.5% of all births in Oregon resulted in an NICU admission (Oregon Center for Health Statistics, 1992). These numbers indicate a rapidly growing number of imperiled infants and consequently a significant number of families who experience the crisis of an NICU admission each year, yet very little research has explored this phenomenon.

Advances in modern technology have made it possible to care for infants who weigh as little as 500 grams or whose gestation is a brief 24 weeks instead of the usual 40 weeks. While survival rates increase with increasing birth weight and gestational age, six month survival rates range from 0-15% (Botkin, 1990). The current trend for treating all imperiled infants in U.S. hospitals is toward the "treat, wait and see" approach (Caplan & Cohen, 1987). This trend has shifted decisions away from whether or not to initiate treatment to withdrawing or withholding treatment later in the neonatal period (Caplan & Cohen). This approach can result in a prolonged waiting period and protracted decision making which has consequences for families and health care providers. Research is needed to empirically describe how technology has affected the decision making process for parents and health care professionals.

In 1982, a highly publicized case of an infant born with Down's syndrome and esophageal atresia forever changed how treatment decisions would be made in NICUs (Newman, 1989). Based on the medical opinion of the attending physician, the parents of this infant chose to not treat him and he subsequently died. His death led to a political controversy over passive euthanasia in NICUs and eventually to the enactment of 'Baby Doe' regulations (Cohen, Levin, & Powderly, 1987). Supporters claimed that the regulations were designed to protect the rights of handicapped newborns (Lantos, 1987). Opponents believe the regulations have undermined the decision making process (Bailey, 1986). A majority of professionals believe that the regulations are not necessary to protect infants' rights, that they interfere with parents' rights to determine the best interests of their children and that they do not allow infant suffering to be considered adequately when making treatment decisions (Kopelman, Irons & Kopelman, 1988). Parents who remember the publicity surrounding Baby Doe cases and the Baby Doe hot-lines may believe that they have no choice about treating their infant and may fear media attention if

they seek alternative choices. The proposed area of study will explore families' experiences with ethical dilemmas in the NICU from several different perspectives.

Roles in the decision making process to withhold and/or withdraw treatment from an infant in the NICU

In the event that a person is incapable of making decisions about his/her medical care, which is certainly the case with infants, someone must act as a surrogate decision maker. Surrogate decision makers may use the advance directive, substituted judgment, or best interest principles for guidance (Buchanan & Brock, 1989). Advance directives require prior legal verification of a person's wishes for treatment options. Substituted judgment requires at least prior knowledge of a person's wishes for treatment. Neither of these approaches is possible with infants.

The best interest principle is most widely used for surrogate decisions regarding infants because infants clearly cannot provide advance directives nor have they any life experiences or values on which to build a substituted judgment (Arras, 1987; Buchanan & Brock; Fost, 1981). Regardless of which principle is used, making decisions about life support for imperiled infants often poses an ethical dilemma.

An ethical dilemma arises when there are two opposing but equally correct choices to resolve a problem (Beauchamp & Childress, 1979). Two opposing choices are equally correct when each comes from a different but valid ethical perspective, for example, utilitarianism and beneficence. Conflict arises when decision makers differ on how they assign priorities or interpret roles and responsibilities (Broom, 1991).

Several authors argue in favor of parents as the decision makers for their infants, provided their decision is not in conflict with the prevailing medical opinion (Asch, Cohen, Edgar & Weisbard, 1987; Duff, 1981; Fost, 1981). This view is supported in law and tradition (Fost, 1986). Some would argue in favor of parents participating in, but not being responsible for making the final decision (Carr, 1989). Although parents are emotional, they are able to participate in making decisions and cope better if they are involved (Schlomann, 1992). It is hard to imagine parents adapting well to outcomes if they are not involved in making crucial decision about their infants' care (Kraybill, 1988). There is little research to support either opinion about the role for parents in making ethical decisions.

Physicians are usually responsible for approaching a family about treatment decisions (Duff, 1981; Fost, 1981). Their primary role is that of scientific and technological expert, which allows them tremendous authority and control in the decision making process (Schlomann, 1992). However, no one individual can be free of bias, which is a strong argument in favor of an approach to decision making in the NICU that uses collaboration with nurses and parents (Bailey, 1986; Rushton & Glover, 1990; Penticuff, 1987; Schlomann, 1992).

Although nurses have the closest contact with infants of all health care providers in the NICU, their role in ethical decision making is unclear. Neonatal nurses identify poorly defined roles in ethical decision making that involves withdrawing and withholding treatment from imperiled newborns as a sources of stress (Elizondo, 1991; Miya, 1989; Penticuff, 1989). One study found that although nurses did not participate in decisions to withhold or withdraw treatment, they were responsible for implementing the decision (Martin, 1989). What impact this has on nurses and how it affects their role in the decision making process needs to be explored through nursing research.

One essential element to resolving conflict is reaching compromise through discussions where participants share mutual respect (Benjamin & Weil, 1987). Many believe that nurses can facilitate collaboration between families and physicians (Novak, 1988; Rushton, 1990; Steele, 1987). Research is needed to determine what role each of the key players, parents, physicians and nurses, plays in the decision making process.

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Effects of Uncertain Prognosis on Treatment Decisions

The conflicting statistics on survival and morbidity associated with survival have contributed to a high level of uncertainty about prognoses for imperiled infants (Arras, 1987, Harrison, 1986). Uncertainty has led to the wait-until-near-certainty approach to dealing with imperiled infants. Virtually every infant receives treatment to provide the greatest chance for survival. Erring on the side of life has a psychological advantage for parents and physicians because it allows medical events to dictate an infant's progression through treatment until a point where futility is virtually certain (Arras, Coulter, Fleischman, Macklin, Rhoden & Weil, 1987). A treatment is futile if its purpose is to achieve a result that is possible but that reasoning or experience suggests is highly improbable (Schneiderman, Jecker and Jonsen, 1990). Using the wait-until-near-certainty approach, physicians avoid making difficult non-treatment decisions and parents are spared the painful task of deciding if treatment or non-treatment is in their infant's best interest.

Uncertainty also has had an effect on the process of making decisions for imperiled infants. An uncertain outcome for an infant contributes to the difficult task of determining the benefits and burdens that the infant and his/her parents will experience as a result of treatment or non-treatment (Rushton & Glover, 1990). Uncertainty contributes to the difficulty of establishing an infant's best interest and who is best capable to determine the infant's best interest. Nurses need more information to clarify how an uncertain prognosis affects treatment decisions for parents, physicians, and nurses before they can develop intervention strategies that will promote family well-being during the crisis of making an ethical decision.

Perceptions of the decision making process to withhold and/or withdraw treatment from an infant in the NICU

Non-research based literature is full of information about parents' experiences when their infants require treatment in an NICU. Many authors relate compelling anecdotes about infants' and parents' experiences in the NICU (Gustaitis & Young, 1986; Lyon, 1985; Shelp, 1986). The most compelling stories come directly from parents (Barthel, 1985; Bridge & Bridge, 1981; Harrison, 1986; Stinson & Stinson, 1983). Parents of a deformed infant describe the details of their son's short life (Harrison, 1986). These parents decided that treatment would not be in their son's best interest. After they refused to consent to treatment for their son, the attending physicians obtained a court order and continued treatment. The parents described visits with their son, where they would find him screaming in pain and tied to his bed to keep him from pulling at his multiple surgical wounds. Before doctors could transfer the infant to a state hospital for long-term care, he died.

One study that illuminated parents' perception of their role in decision making found that parents do not perceive themselves as having an active role in decision making in the NICU. Parents reported that they were not objective when making decisions regarding their infants, that they felt treatment decisions were within the staff's sphere of authority and that they did not report astonishment at treatment implications until long after the outcome of the decision was known (Pinch & Spielman, 1990). The realization that their child did not have to receive maximum treatment comes for many when their child survives neonatal intensive care, only to experience long-term institutional care, repeated hospital admissions and severe developmental disabilities. In a later study, Pinch (1990) found that parents perceived themselves as passive observers in the decision making process in the NICU. At least one author suggests that this passive participation results when parents receive only one opinion about treatment options (Harrison, 1986)

Ironically, physicians report that parents' lack of knowledge is a factor in presenting limited treatment options and restricting information given to parents. This is a common strategy used by physicians to protect parents from the stress of decision making (Fost, 1991; Harrison, 1986). Even though some physicians report limiting parents' involvement in treatment decisions (Fost, 1981), when asked, health care professionals believe that they actively involve parents in decision making (Pinch &

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Spielman, 1989). Clearly a gap exists between health care professionals' and parents' perceptions of the decision making process in the NICU.

Perhaps this gap can be explained by how the NICU is perceived. Parents and nurses respond to the NICU by focusing on the infants' best interest and quality of life, a relational perspective (Schlomann, 1992). This approach is consistent with what Duff (1987) calls "close-up" ethics. This approach acknowledges the importance of individuals and feelings as well as ethical principles. It requires active participation of parents and health care professionals. Because it is founded on education and empathy, practicing close-up ethics is difficult (Duff, 1987).

Physicians, on the other hand, focus on technology to solve problems. This may be called the rational perspective (Schlomann, 1992). This approach is what Duff (1987) would call "distant" ethics since it relies on abstract principles. Distant ethics is easier to practice because it relies on rules derived from scientific, philosophical or legal analysis (Duff, 1987). Bridging the gap between a relational and rational perspective can best be accomplished by using a combined approach. In fact, a blending of the two perspectives has been suggested as the most ideal approach to dealing with ethical dilemmas (Blustein, 1989; Rushton & Glover, 1990).

Nurses need more information to better understand what families experience when they are faced with an ethical dilemma in the NICU. Research is needed that will describe parents' experiences with ethical decision making in the NICU, describe intervention strategies that families identify as helpful in improving their ability to cope with the stress of facing an ethical dilemma in the NICU, and explore NICU nurses' experience in caring for imperiled infants and their families. The proposed research training program will focus on these aims. The future dissertation that will culminate the research training program will generate knowledge that will guide NICU nurses in their care of imperiled infants and their families.

3) Experimental Design and Methods

Since I have yet to begin my coursework in the doctoral program, it would be premature to determine the experimental design and methods I will use to conduct my dissertation research. However, I am committed to the proposed area of study and can predict the research methods that will be most useful and effective for exploring families' experiences with withholding and/or withdrawing treatment from their imperiled infants in the NICU. Because there is limited nursing knowledge in this area, qualitative research methods offer the most potential for generating rich descriptions of these phenomena. Four of the five specific potential research questions listed earlier are consistent with the the purposes of qualitative research methods, which are description, hypothesis generation, understanding relationships and causal processes, and illustrating the meaning of relationships (Polit & Hungler, 1987).

Qualitative Research Methods

What families experience when faced with withholding and/or withdrawing treatment from their imperiled infants in the NICU is complex, context-dependent, and subjective. Qualitative research designs are most useful as a starting point when, as in this case, available knowledge is limited. Because of the complexity, contextual dependency, and sensitivity of the topic, a triangulation of methods probably will be used to collect data. Interviews, document reviews, and participant observations are all potential methods to be used in data production.

Structured and semi-structured interviews would be helpful in gathering detailed perceptions from families who experience this phenomenon. Subjects would be imperiled infants' parents and health care providers. Interviews allow the researcher to be flexible and sensitive to families' needs where quantitative methods do not. Interviews also offer the researcher the opportunity to be compassionate toward and interact closely with families. Face to face interviews facilitate information exchange and clarification. Some potential interview questions for parents include; 1) Describe your experience in the NICU. 2) Tell me about the treatment options for your infant. 3) Can you tell me about the prognosis for

INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

your infant? 4) Is there any uncertainty about what may happen to your infant? 5) How does this make you feel? 6) Do you feel you have played an active part in making decisions about your infants' care? 7) Who has been influential in making decisions about you infants' care? 8) Tell me about the process of making decisions for your infant. 9) What can we as health care professionals do to help you at this time? Each of the above questions can be modified to elicit the same information from the infants' care providers.

Reviewing documents is the only way to observe the official record of an infants' status and how it relates to interactions with families. Document review combined with interviews will confirm or deny inconsistencies between verbal and written reports of families' experiences. Records will be examined for a variety of information including information about the infants' prognosis, information on the infants' tolerance of procedures and changes in assessment of the infants' status. Documentation of parents' interactions with their infant and their infants' providers is essential information to look for in the record. Documentation of the frequency, context, and content of interactions is important to note.

Participant observation is the appropriate method for capturing the phenomenon under study as it occurs. Observing and interacting with families and health care professionals as they cope with the dilemma of withholding and/or withdrawing treatment from an infant could provide valuable information relevant to nursing knowledge in this area.

Sample and Setting

Although the term family implies a broad network of familial relations, including aunts, uncles, grandparents and siblings, it is primarily the parents of an imperiled infant who must face the legal, emotional and financial burden of caring for their infant. Therefore, for the purposes of the proposed study, family refers to the parents of an imperiled infant. Parents will be the primary subjects for this research project. Health care providers will also be interviewed as subjects. The imperiled infant is a subject for the study to the extent that his/her condition will determine which parents and care providers to include in the study.

Parents of imperiled infants have a full range of socioeconomic backgrounds, education, ethnicity and health insurance coverage. Because the crisis of facing an ethical dilemma regarding withholding and/or withdrawing treatment from an infant is a nondiscriminatory event, there are no plans to limit parents from this proposed study using any ethnic, social, racial, educational, financial or religious criteria. An infants' condition will be the primary criterion used to include parents in this study.

Infants become imperiled for many different reasons. There are some obvious cases, such as congenital malformations, that may or may not be lethal. Some infants suffer birth asphyxia which may result in varying degrees of impairment. Many infants are born prematurely and become imperiled as a result of life sustaining treatments they receive. It is difficult to predict in advance which infants will present with a situation in which withdrawing and/or withholding treatment is considered. In the proposed study, criteria that may be used to identify imperiled infants include infants born at less than 26 weeks gestation, infants with a hypoplastic left heart, infants with trisomy 13 or 18, or with multiple system failures. An imperiled infant is any infant for whom a discussion of withholding or withdrawing treatment is being considered. The only criteria for inclusion in this study is the consideration of withholding and/or withdrawing treatment for any reason from an infant.

Care providers involved in the care of imperiled infants can supply valuable information relevant to this area of study. Many providers are involved in the care of imperiled infants, including physicians, nurses, respiratory therapists, social workers, physical therapists and technicians from many different support services. This investigation is most interested in health care providers who have the most intimate and consistent contact with an imperiled infant. Health care professionals to be interviewed will probably be limited to physicians, nurses, and respiratory therapists. Other providers, such as clergy and social workers who have close contact with families of an infant also may be a valuable source of information.

INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

Although it would be premature to stipulate sample size in advance of specifying the definitive research questions and exact study methods, standard guidelines for sample size will be followed. A large enough sample to achieve adequate variability of infant and parent characteristics will be sought.

This proposed study will take place at more than one NICU. The reason for using two sites for the proposed study is to gather data from diverse areas where the medical approach and philosophy of family care may vary. It is also expected that using two locations will increase the diversity of the patient populations and therefore expose the researcher to families with varying characteristics. The two potential locations, Oregon Health Sciences University, (OHSU) and Emanuel Hospital, are both located in Portland, Oregon. OHSU is a major tertiary care facility and a public teaching hospital. Emanuel is a private hospital. The environments of the two NICUs are completely different. The unit at OHSU is crowded, needs renovation, and patients usually have a high level of acuity. The unit at Emanuel has been renovated recently, has ample space and the population is less acute. OHSU provides cardiac surgery services for all neonates in Portland. Emanuel offers the only extracorporeal membrane oxygenation program in Portland.

Data Collection Procedures

There are two potential ways to identify infants meeting criteria for the study, weekly chart reviews and referral from health care professionals involved in the care of an infant whom they feel meets criteria. Once an infant has been identified as meeting criteria, the attending physician responsible for overseeing care of the infant will be contacted. Once the attending physician has given permission and primary care providers have identified an appropriate time to approach parents, the parents of the identified infant will be invited to participate in the study. Parents whose infant is critically ill are under a great deal of stress and their mental health must always be considered before approaching them to participate in a study that is potentially emotionally stressful. Initially, parents will be provided with information about the purpose of the study and methods to be used. Parents will be given time to discuss participation in the study with each other in private.

Both physicians and nurses working in the NICUs where the study will be conducted will be informed of the study and asked to serve as referring agents for infants whose care may require examining the option to withdraw and/or withhold treatment. Some families may be identified as potential subjects immediately after the birth of their infant because of their infants' condition. Informing these parents of the study early in their infants' course of treatment may increase the likelihood that they will wish to participate. Once parents consent to participate in the study, care providers involved in the case will be identified and invited to participate. Once their consent is obtained, arrangements for an interview will be made.

To avoid distractions from the NICU, interviews will be conducted as far away from the NICU as possible. Distance from the NICU will depend on how stable an infant is and whether or not the infant is still receiving care in the NICU. Parents who wish to participate in the study before a decision has been made may wish to remain close to the NICU if their infant is in critical condition. Parents who wish to participate after a decision has been made may wish to be far away from the NICU depending on the outcome of the decision. Care providers will be given the same choices for location for interviews. Distance from the NICU is not as crucial as the room where the interview takes place. Parents and care providers must be assured of privacy and they must be comfortable when the interview takes place. Both NICUs have rooms either on the unit or close by, which would provide comfort and privacy for parents and care providers during an interview.

All interviews will be conducted by the investigator. With permission from respondents, interviews will be tape recorded and later transcribed to facilitate data analysis. The interview will have some structure but will allow subjects time to voice concerns and talk about things not necessarily pertinent to the study. Parents and care providers must be assured of confidentiality. Parents must understand that

INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

any questions they have about their infants' condition or treatment should be directed to the care providers for their infant. Care providers may also have questions that should be directed to other care providers. If subjects have concerns and are unsure of whom to approach, the investigator will act as a resource and identify people whom subjects can approach for information and clarification.

As mentioned earlier, medical records will be reviewed on a weekly basis to identify potential subjects for the study. Before subjects have been confirmed as participants in the study, medical records will only be reviewed for diagnostic and prognostic information that would be helpful in identifying an infant as potentially meeting criteria. Once parents have consented to participate in the study, their infants' complete medical record initially will be reviewed for identification of providers, information about treatments received, prognosis, and demographic data. During the course of the study, infants' medical records will be reviewed on a weekly basis. Crucial information to look for includes documentation of interactions between parents and providers, and parents and infants, and interactions between the various providers.

Subjects will be observed at crucial times during the course of an infants' treatment. Ideally parents and care providers will be observed during the initial discussion with parents about withholding and/or withdrawing treatment from their infant. Parents will be observed during at least two interactions with their infant, one before the discussion about treatment options and one after the discussion. Providers will be observed while giving routine care to the infant and when interacting with parents before and after the discussion about treatment options. Parents and providers will be observed for facial expressions, amount of physical contact with the infant, verbal interactions with the infant and verbal interactions with each other. Interactions with subjects during observation times will be avoided.

Data Analysis

Demographic data from patient records will be compiled as descriptive statistics. Relevant data from records will also be compared against interview information for consistency. Interviews will be transcribed verbatim. Analysis of information from health care professionals' interviews will focus on comparison of verbal descriptions of events with written documentation of the same events and comparison of provider's views with what parents say about providers' attitudes. Analysis of information from parent interviews will focus on describing the experiences of parents during their infants' stay in the NICU with particular emphasis on the events surrounding the discussion of withholding and/or withdrawing treatment from their infant. The goal is identification of concepts, identification of relationships and processes and eventual hypothesis generation.

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5) Human Subjects

The proposed study will be reviewed and approved by Human Subjects Committees at both intended data collection sites.

Facing a crisis of this nature must be stressful for parents. Participation in this study poses a moderate threat to parents' mental health through an increase in the stress associated with this crisis. Parents who participate in the interview process also risk altering the relationship they have established with care providers. However, parents also may experience a benefit from having the opportunity to talk to a compassionate and knowledgeable listener who will guarantee their privacy. It is essential that parents who agree to participate in any research study related to this topic be assured that they will suffer no repercussions if they choose to withdraw from the study at any time for any reason.

Even though care providers face critically ill infants on a daily basis, it never becomes routine. When an infant has been identified as imperiled and may not survive, care providers also experience emotional stress. Providers risk the same threat to their mental health as parents. Care providers who participate in the interview process also risk altering the relationship they have established with parents. But care providers also may receive the same potential benefit that parents receive. Confidentiality for participating providers is essential, especially if they have an unpopular opinion about the events surrounding the care of an imperiled infant. They must also be assured that their desire to withdraw from the study will be respected and complied with at any time during the course of the study.

c) Respective Contributions

The general idea for the proposed dissertation was my own. Dr. Mark Merkens, Dr. Virginia Tilden and Dr. Mary Anne Curry were helpful in clarifying my ideas and the plan for the research study, and provided help editing the grant application.

d) Selection of Sponsor and Institution

I selected Dr. Tilden as principal sponsor because of her expertise in the area of health care ethics, her research experience, her ability to share her knowledge and her talent for inspiring students. Her role as program director of an Institutional NRSA Research Training Program on family health and her background in mental health of families provides outstanding qualifications for sponsoring my program. My association with Dr. Tilden began in 1982 when I was an undergraduate student at OHSU. At that time, I was privileged to be involved in Dr. Tilden's efforts to develop an ethics curriculum for the nursing school.

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INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

Dr. Tilden is a founding member of the OHSU Center for Ethics in Health Care. As assistant director, she serves as the official liaison between the School of Nursing and the Center (0.1 FTE) and co-chairs the Center's Ethics Research Task Force. Dr. Tilden has completed the University of Washington Certificate Program in Health Care Ethics under the guidance of Dr. Albert Jonsen, Professor of Ethics in Medicine at the University of Washington School of Medicine. She serves as an ethics facilitator of the University Hospital's Nursing Ethics Rounds, a twice monthly clinical ethics forum of clinical nursing ethics dilemmas, and she serves as a member of the OHSU University Hospital Ethics Consult Service.

Dr. Tilden currently is the principal investigator of an NCNR funded research project titled "Family Decision Making for Incapacitated Patients." The purpose of this study is to discover knowledge about the experiences and reasoning processes of families facing ethical decisions about withholding or withdrawing life support from decisionally incapacitated, critically ill family members. This study is closely related to my proposed study, the major difference being that the critically ill family member I wish to focus on is the infant who has never been decisionally competent. Dr. Tilden is nationally and internationally recognized as a leader in research involving social support, stress, family nursing, and measurement. I feel honored to have the opportunity to work with Dr. Tilden as a research fellow.

I first met Dr. Merkens at the Summer Seminar in Health Care Ethics at the University of Washington. At that time I was impressed with Dr. Merkens' enthusiasm for ethical dilemmas involving pediatric patients. We discussed at length concerns regarding ethical dilemmas relating to pediatric patients and how these differ from dilemmas regarding adults. I have been fortunate to work in clinical practice with Dr. Merkens and have seen first-hand his compassion and skill working with pediatric patients and their families.

Dr. Merkens is an adjunct Associate Professor in the School of Medicine at OHSU. He maintains his clinical practice at the Child Development and Rehabilitation Center (CDRC) and works with children who have chronic physical conditions and medical illnesses. Many of his patients are former NICU patients, so he has first-hand knowledge with families who have experienced the crisis of an NICU admission for their infant. His special area of interest is directed toward the impact of physical conditions on children and family coping. He has completed the Health Care Ethics certification program at the University of Washington School of Medicine and serves as a scholar/consultant with the Center for Ethics in Health Care at OHSU. Dr. Merkens and Dr. Tilden serve together on the OHSU University Hospital Ethics Consult Service. As co-sponsor of my research program, Dr. Merkens will bring a medical perspective to the proposed area of interest.

I chose the graduate program at the OHSU School of Nursing for a number of reasons. Students are exposed to experiences that emphasize integration of practice with theory and research. The doctoral programs at the School of Nursing emphasize development of expertise in theory building and research that contributes to the knowledge base of nursing. The faculty and dean have an excellent research reputation. The support services available to graduate students are outstanding. They include the Biomedical Information and Communication Center, the Office of Research Development and Utilization and of particular interest to me, the Center for Ethics in Health Care. Finally, a health sciences university offers opportunities to interact with health scientists from many different disciplines, and to collaborate with scientists from other disciplines on questions and problems of mutual concern.

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INDIVIDUAL NRSA APPLICATION—CONTINUED*(To be completed by sponsor. Also complete Items 9 through 14 on Page 1. Follow instruction sheet.)*NAME OF APPLICANT (*Last, first, middle initial*)**Wocial, Lucia D.****30. BIOGRAPHICAL SKETCH OF SPONSOR**

NAME	POSITION TITLE	BIRTHDATE (<i>Month, day, year</i>)
Tilden, Virginia P.	Professor/Associate Dean for Research	June 25, 1945

EDUCATION (Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)

INSTITUTE AND LOCATION	DEGREE	YEAR CONFERRED	FIELD OF STUDY
Georgetown University, Washington, DC	BS	1967	Nursing
Univ. of California, San Francisco, CA	MS	1971	Psych. Nursing
Univ. of California, San Francisco, CA	Post-MS	1972	Adult Psych. Nsg.
Univ. of California, San Francisco, CA	DNSc	1981	Nursing Science
University of Washington, Seattle, WA	Certificate	1990	Hlth Care Ethics

RESEARCH AND/OR PROFESSIONAL EXPERIENCE: Concluding with present position, list in chronological order previous employment, experience, and honors. Include present membership on a Federal Government public advisory committee. Specify the total number of publications and list, in chronological order, the titles and complete references to all publications during the past three years and to representative earlier publications pertinent to this application. **DO NOT EXCEED 2 PAGES.**

PROFESSIONAL EXPERIENCE

1982-1987 Associate Professor, Department of Mental Health Nursing, Oregon Health Sciences University, School of Nursing, Portland, Oregon.

1988-present Professor, Department of Mental Health Nursing, Oregon Health Sciences University, School of Nursing, Portland, Oregon.

1989-present Assistant Director, Center for Ethics in Health Care, Oregon Health Sciences University, Portland, Oregon.

1990-present Program Director, Institutional National Research Service Award on Research of Families, NCMR, NIH, (1990-1995, \$718,608).

1991-present Associate Dean for Research, Oregon Health Sciences University, School of Nursing, Portland, Oregon.

HONORS

1966 Sigma Theta Tau Honor Society in Nursing

1967 Cum Laude Graduate and Nurse of the Year Award, Georgetown University

1981 Valedictorian Doctoral Class, University of California

1987 Marquam Hill Lecturer, Oregon Health Sciences University

1987 The President's Excellence in Teaching Award, Oregon Health Sciences University

1988 Outstanding Graduate Faculty Award, Oregon Health Sciences University

1988 Fellow, American Academy of Nursing

ELECTED NATIONAL OFFICES/SERVICE

1985-1987 Sigma Theta Tau International Research Committee

1985-1987 Western Society for Research in Nursing Executive Committee

1987-1990 American Nurses Association Cabinet on Nursing Research

1988-1989 Western Society for Research in Nursing Nominating Committee Chairperson

1990-1992 Western Society for Research in Nursing Executive Committee (Chair in 1991-1992)

1991 Scientific Study Section Member, National Center for Nursing Research, NIH, Bioethics and Clinical Decision Making

1992-1994 American Nurses Association Council of Nurse Researchers Executive Committee

FUNDED RESEARCH

1980-1982 Co-Principal Investigator, "Multivariate Predictors of Pregnancy Complications", UCSF Academic Senate Funds, \$5,000.

1986 Principal Investigator, "Instrument Development for Social Support", BRSG grant, \$3,000.

1986-1988 Principal Investigator, "Development of Measures for Social Support", National Center for Nursing Research/NIH, 1R01 NR 01184; \$139,000.

INDIVIDUAL NRSA APPLICATION—CONTINUED*(To be completed by sponsor—follow instruction sheet.)*NAME OF APPLICANT *(Last, first, middle initial)***Wocial, Lucia D.****31. SPONSOR'S RESEARCH AND TRAINING SUPPORT (Use continuation pages if necessary.)**

List, in three separate groups: (1) active support; (2) applications and proposals pending review and/or funding; (3) applications and proposals planned or being prepared for submission. Include all Federal, non-Federal, and institutional grant and contract support. If none, state "NONE." For each item give the source of support, identifying number, project title, name of principal investigator/program director, time or percent of effort on the project, annual direct costs, and entire period of support. (If part of a larger project, provide the titles of both the parent project and the subproject, and give the annual direct costs for each.) *Identify the research support funds that will be available to the applicant during the period of the proposed award.*

(1) ACTIVE SUPPORT:

- (a) National Center for Nursing Research
- (b) 1 T32 NR07061
- (c) "Research of Families in Health, Illness, and Transition"
- (d) Virginia P. Tilden (e) 15%
- (f) Yr 01, \$46,563; Yr 02, \$112,390; Yr 03, \$163,524; Yr 04, \$165,849; Yr 05, \$186,432
- (g) 2/1/90-1/31/95

- (a) Meyer Memorial Trust
- (b) N/A
- (c) "Center for Ethics in Health Care at Oregon Health Sciences University"
- (d) Susan W. Tolle, M.D. (e) 10%
- (f) \$50,000 per year, totalling \$250,000
- (g) 7/1/89-6/31/94

- (a) National Center for Nursing Research
- (b) Not yet assigned
- (c) "Family Decision Making for Incompetent Patients"
- (d) Virginia P. Tilden (e) 10%
- (f) Yr 01, \$24,602; Yr 02, \$10,396
- (g) 9/15/91-8/31/93

NOTE: No funds from the above projects would be used for the applicant during the period of proposed award.

- (2) Pending: None.
- (3) Planned: RO1 application to NCNR on family decision making for incapacitated patients.

32. PREVIOUS FELLOWS/TRAINEES

Give total number of pre- and postdoctorals and provide information on a representative five. List their present employing organizations and position title or occupation.

YEAR	STUDENT	INSTITUTION	EMPLOYMENT
1984-86	Cecelia Capuzzi	Pre-doc Portland State	OHSU-Associate Professor
1988-90	Barbara May	Pre-doc OHSU	Linfield School of Nursing Assistant Professor
1989-92	Pat Butterfield	Pre-doc OHSU	OHSU-Assistant Professor
1988-92	Sarah Porter-Tibbetts	Pre-doc Portland State	OHSU-Assistant Dean for Student Affairs
1992- present	Anne Rosenfeld	Pre-doc OHSU	Current Predoctoral student
1991	Sophia Harrell	Post-doc OHSU	Current Post-doctoral fellow through 1/93
1992	Ann Hirsch	Post-doc OHSU	Current Post-doctoral fellow through 5/94

<p align="center">INDIVIDUAL NRSA APPLICATION—CONTINUED</p> <p align="center"><i>(To be completed by sponsor. Also complete Items 9 through 14 on Page 1. Follow instruction sheet.)</i></p>	<p>NAME OF APPLICANT <i>(Last, first, middle initial)</i></p> <p>Wocial, Lucia D.</p>
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30. BIOGRAPHICAL SKETCH OF SPONSOR

NAME	POSITION TITLE	BIRTHDATE <i>(Month, day, year)</i>
Mark J. Merkens, MD	Attending Physician Adjunct Associate Professor	December 30, 1946

EDUCATION (Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)

INSTITUTE AND LOCATION	DEGREE	YEAR CONFERRED	FIELD OF STUDY
Earlham College, Richmond, IN	BA	1968	Chemistry
State Univ. of N.Y., Upstate Medical Ctr, Syracuse	MD	1972	Medical School
Upstate Medical Center, Syracuse, NY	Residency	1975	Pediatrics
Vanderbilt University Med. Ctr, Nashville, TN	Fellowship	1982	Pediatrics
University of Washington, Seattle, WA	Med.Ethics	1991	Cert., Medical Ethics

RESEARCH AND/OR PROFESSIONAL EXPERIENCE: Concluding with present position, list in chronological order previous employment, experience, and honors. Include present membership on a Federal Government public advisory committee. Specify the total number of publications and list, in chronological order, the titles and complete references to all publications during the past three years and to representative earlier publications pertinent to this application. **DO NOT EXCEED 2 PAGES.**

Certifications

- Diplomat, American Board of Pediatrics
- Diplomat, National Board of Medical Examiners

PROFESSIONAL EXPERIENCE

- 1975-1980 Pediatrician, Oak Orchard Community Health Center, Brockport, New York
- 1980-1982 Instructor of Pediatrics, Division of General Pediatrics, Vanderbilt University Medical Center, Nashville, Tennessee
- 1982-1984 Assistant Professor of Pediatrics, Chronic Disease Section, Department of Pediatrics, Pritzker School of Medicine, University of Chicago
- 1984-1989 Deputy Director, Monroe County Health Department, Rochester, New York
- 1985-1989 Clinical Assistant Professor and Attending Physician, Department of Pediatrics, Strong Memorial Hospital, University of Rochester, New York
- 1989-present Adjunct Associate Professor, Department of Pediatrics, Oregon Health Sciences University, Portland, Oregon
- Senior Scholar, Center for Ethics in Health Care, Oregon Health Sciences University, Portland, Oregon
- Clinical Ethics Consult Team Member, Center for Ethics in Health Care, Oregon Health Sciences University, University Hospitals, Portland, Oregon
- 1989-present Attending Physician, Shriner's Hospital for Crippled Children
- 1989-present Attending Physician, Child Developmental Rehabilitation Center (CDRC)

PROFESSIONAL ORGANIZATIONS

- 1977-present American Academy of Pediatrics
- 1990-present OPS Chapter Committee of Children with Disabilities
- 1990-present OPS Chapter Healthy Children Program Coordinator
- 1978-1979 Chapter 1, District 2 (New York): Chairman, Community Health Committee
- 1980-1990 Ambulatory Pediatric Association
- 1980-1990 Association for the Care of Children's Health

PUBLICATIONS

Merkens, M.J. (1991). From intensive care unit to home: The role of pediatric transitional care. In Hochstadt, H.J. & Yost, D.M. (Eds.), The Medically Complex Child: Transition to Home Care, pp.61-78. New York: Harwood.

INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGENAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

- Merkens, M.J. (1990). A pediatric chronic illness transition unit. Children's Health Care, Winter, 4-9.
- Merkens, M.J., Perrin, J.M., Perrin, E., & Gerrity, S. (1989). Awareness of secondary adjustment in chronically ill children by primary care physicians. Journal of Behavioral and Developmental Pediatrics, 10(1), 1-6.
- Merkens, M.J. & Weiner, L.B. (1975). Lung aspirate diagnosis in pediatric pneumonias. Pediatric Research, 9, 402. (#807 Yearbook of Pediatrics, 1977).
- Perrin, J.M. & Merkens, M.J. (1979). Blood lead levels in a rural population: Relative elevations among farm worker children. Pediatrics, 64, 540.

Total number of publications:

Articles = 3

Book Chapters = 1

Abstracts = 1

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**INDIVIDUAL NRSA APPLICATION—CONTINUED
FACILITIES AND COMMITMENT STATEMENT**
(To be completed by sponsor—follow instruction sheet.)

NAME OF APPLICANT (Last, first, middle initial)

Wocial, Lucia D.

In the space below and on continuation pages, complete the following items. Identify each item by number and title.

33. Training Plan, Environment, Research Facilities.

Describe the research training plan for the applicant. Include such items as classes, seminars, and opportunities for interaction with other groups and scientists. Describe the research environment and available research facilities and equipment. Include information that will help reviewing groups evaluate the applicant and the proposed training. Indicate the relationship of the proposed research training to the applicant's career. Describe the skills, techniques, etc., that the applicant will learn and relate these to the applicant's career goals.

34. Number of fellows/trainees to be supervised during the fellowship. Indicate Pre- or Postdoctoral.

35. Applicant's Qualifications and Potential for a Research Career.

36. Human Subjects/Vertebrate Animals Use and Description, Hazardous Materials and Procedures.

33. Training Plan, Environment, and Research Facilities.**TRAINING PLAN**

The basic structure for Lucia Wocial's research training program was developed using the doctoral program in nursing at the Oregon Health Sciences University (OHSU). The requirements for the PhD in nursing at OHSU are designed to emphasize the development of expertise in theory building, research conduct, and utilization with the goal of contributing to the knowledge base for nursing practice. Beyond the required coursework, Lucia has designed a program of specialized study within the focal area of Nursing and Health Care Delivery. Lucia has chosen to develop her minor work in health care ethics. This program of specialized study will enable Lucia to develop practice-relevant theory, use appropriate state-of-the-art methods to study complex nursing problems and analyze nursing research and practice.


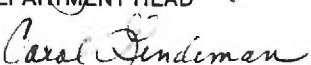

The following is a summary of the Doctor of Philosophy degree requirements at the OHSU School of Nursing and a description of the courses in Lucia Wocial's program of study.

CORE COURSES OHSU Doctoral Program

NUR 611 Design and Analysis for Complex Nursing Problems (4 Credits) This course focuses on design and analysis options which are congruent with the complexity of research questions derived from nursing practice. Laboratory experience in the use of complex multivariate techniques is included.

NUR 612 Conceptualization and Measurement of Nursing Variables (4 Credits) This course focuses on the conceptualization and operationalization of variables in nursing research and practice. The conceptual and technical aspects of instrument development and testing are explored. The laboratory experience is designed to assist the student to begin construction and evaluation of empirical measures for use in research and practice.

37. **CERTIFICATION:** We, the undersigned, certify that (a) the information herein, including involvement of Human Research Subjects, Recombinant DNA Research, and Vertebrate Animals, is true and complete to the best of our knowledge; (b) if this application results in an award, appropriate training, adequate facilities, and supervision will be provided; and (c) we will abide by applicable Public Health Service policies in effect at time of award. A willfully false certification is a criminal offense (U.S. Code Title 18, Section 1001).

SIGNATURE	TYPED NAME	OFFICE TELEPHONE	DATE
SPONSOR 	Virginia P. Tilden, DNSc, FAAN	503/494-3857	Sept. 8, 1992
DEPARTMENT HEAD 	Carol Lindeman, RN, PhD, FAAN	(503)494-7790	9/8/92
OFFICIAL SIGNING FOR SPONSORING INSTITUTION 	Dennis Borden, PhD Asst. Vice Pres.,	503/494-7784	9/8/92

INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

NUR 613 Design and Analysis of Change in Nursing Practice (4 Credits) The concept of change is central to theory-based nursing practice and inquiry, since change is both the goal and context of nursing intervention. This course emphasizes innovations in research design necessary to test prescriptive theory for practice. The laboratory experience provides opportunities to explore the consequences of alternative methods of measuring and analyzing change in a variety of designs.

NUR 614 Nursing Theory Analysis (3 Credits) This course focuses on the analysis of theory and the consequent criteria for theory evaluation. Selected theories used by nurses are analyzed. Emphasis is placed on the relationship between research, practice, and theory as a basis for theory development.

NUR 615 Innovations and Context of Nursing Practice (3 Credits) This seminar focuses on analyzing ways in which the nursing profession uses its knowledge and practice base to the advantage of client populations. Emphasis is on the potential impact of theory and research on provider relationships and innovations in the larger health care system.

NUR 616 Nursing Theory Development (3 Credits) This seminar is directed toward the creation of prescriptive nursing theory. It provides the doctoral student involved in dissertation research with experience in theory development that crosses focal areas. Source materials for the seminar come from students' areas of concentration and research.

FOCAL AREA COURSES Nursing and Health Care Delivery (15 credits).

NUR 539: Resource Allocation in Health Organizations (3 Credits) This course examines the development, implementation and management of financial and human resources in health services organizations. Productivity improvement, use of monitoring systems, and the impact of reimbursement systems on resource allocation and utilization will be examined.

NUR 580: Health Policy Development I (3 Credits) This course focuses on the context in which health policy decisions are made. Political processes are analyzed vis a vis current health care issues. Major models for evaluating political processes and behavior are examined. Development of practical skills or strategies, needed by political activists, are emphasized.

NUR 581: Health Policy Development II (3 Credits) This course focuses on policy-making in health care; particularly on the development, implementation, and evaluation of policy related to health care delivery. Current health policy issues are used to analyze relationships between policy and health care delivery, and to analyze models for implementation and analysis of policy. Research design and methods used in policy evaluation are explored in relation to evaluation of specific policy proposals and programs. A required field experience in a governmental, administrative, or community agency affords the student the opportunity to apply course content, to test models for policy and political analysis, and to refine political skills in a realistic setting.

NUR 637: Cost-Benefit Analysis in Health Care (3 Credits) This course defines and explains cost-benefit analysis (CBA) and cost-effectiveness analysis (CEA). It illustrates applications of CBA/CEA to current policy issues in health care and points out common analytic errors. The course does not emphasize formal economic theory, per se, and it does not require any specific preparation in economics, mathematics, or statistics. The ultimate purpose is to demonstrate the usefulness and limitations of CBA and CEA when applied for the purposes of program evaluation and resource allocation in the health services sector. Specific topics to be covered include a basic review of health care financing, definition of cost-effective health care, description of the methods of CBA and CEA, review of the literature of CBA/CEA in health care, and identifications of future research needed to improve the state of the art in CBA and CEA.

INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

NUR 648: Development and Evaluation of Measures for Caregiving (three quarters, 6 credits). This course focuses on the development and evaluation of measures of family caregiving. Emphasis is placed on the special features of measurement with older populations, and on the process of collaboration in research.

MINOR AREA COURSES

PH 604: Readings and Conference: Theories and Models for Bioethical Decision Making (3 Credits) This course will be guided by Dr. Michael Garland, DSc. Rel., medical ethicist, Associate Professor of Public Health and Preventative Medicine, Associate Director of the OHSU Center for Ethics in Health Care, and past-President of Oregon Health Decisions. The course will take an interdisciplinary approach to the analysis of bioethical decision making models.

NUR 505: Readings and Conference: The Role of the Bedside Nurse in Ethical Decision Making (3 Credits) This course will be guided by Dr. Virginia Tilden, DNSc, Professor and Associate Dean for Research, School of Nursing and Director of the Office of Research Development and Utilization. This course will examine the roll of the bedside nurse in ethical decision making from an historical perspective. This course will also examine potential future roles for nurses in ethical decision making based on guidelines in Nurse Practice Acts and professional policy statements.

UNIVERSITY OF WASHINGTON School of Medicine

PH 540A Seminar in Ethics (5 Credits) The primary focus of the seminar will be on Thomson's book, The Realm of Rights, particularly as it bears on the following questions: What are rights? What is the relation between rights, duties and goals? What rights are morally fundamental? What is the moral status of the commonly asserted rights to life, liberty, and property?

MHE 474 Justice in Health Care (5 Credits) This course examines the ethical problem of allocating scarce medical resources. Emphasis is on fundamental principles of justice that support alternative health policies.

MHE 522 Ethical Problems Surrounding Death (3 Credits) This course investigates issues arising in the care and treatment of dying patients and their families, including truthful disclosure, use of life-supports, "euthanasia," and coping, death, and grief. The intersection of patient and professional values related to care in terminal phase of illness is also examined.

MHE 535 Medical Ethics and Jurisprudence (3 Credits) This course focuses on relationship between bioethics and the law, a review of the basic concepts of both disciplines, and their theoretical and practical connections. An analysis of principal legal cases and statutes illustrates such issues as informed consent to treatment, foregoing life support, research with human subjects, confidentiality, and allocation of health care resources.

ADDITIONAL NON-DEGREE TRAINING

Certification in Health Care Ethics through the University of Washington School of Medicine This course is sponsored by the Department of Medical History and Ethics, Continuing Medical Education, and University of Washington Extension. Health care professionals accepted for the program attend two successive summer seminars and complete distance learning modules during the intervening year. The purpose of the program is to give professionals some advanced training in addressing ethical dilemmas that occur in the course of clinical practice.

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INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

OREGON HEALTH SCIENCES UNIVERSITY

ELECTIVES

NUR 607: Family Research Issues (1 Credit per term) This doctoral seminar focuses on conceptual, methodological, and practice issues that arise in the conduct of research focused on nursing and health care delivery to families in health, illness and transition. Seminar topics will be identified by the group and will arise out of the needs of the group.

NUR 650: Seminar in Qualitative Research (2 Credits) This course focuses on concepts underlying qualitative analysis and the use of those procedures in research and practice settings. Students will use computerized statistical programs to apply selected inferential statistical procedures to a research question in nursing.

RESOURCES AND ENVIRONMENT

OREGON HEALTH SCIENCES UNIVERSITY

The Oregon Health Sciences University (OHSU) is one of eight universities in the Oregon State System of Higher Education and the only one devoted exclusively to health sciences. The School of Nursing together with the Schools of Medicine and Dentistry and the University Hospital and Outpatient Clinics comprise OHSU. Also located on its campus are the Child Development and Rehabilitation Center, Shriners Hospital for Crippled Children, and the Veterans Administration Medical Center. The University is accredited by the Northwest Association of Colleges and Universities. The missions of the University include the education of health professionals, health-care research, community service, and patient care.

OHSU ranks within the top 100 institutions in the United States in federal support, including research and development funding. OHSU scientists are credited with many medical, surgical, and behavioral science discoveries now saving or improving lives throughout the world. From the development of one of the most widely used artificial heart valves to studies on how light and hormones influence biological depression, OHSU faculty members have made well-known contributions in the area of research. This research offers a foundation for training scholars and teachers and for higher standards of health care for the people of Oregon. OHSU students are encouraged to participate in research and are offered many opportunities to do so during their academic and clinical training.

The Vollum Institute for Advanced Biomedical Research, the Center for Ethics in Health Care, the Western Mental Health Research Center, the Center for Research on Occupational and Environmental Toxins (CROET), as well as the new regional eye center add to the OHSU's growing national reputation as a biomedical research institution. The Biomedical Information Communication Center (BICC) consolidates the activities of the health sciences library, biomedical communications, academic and research computing, telecommunications, and medical informatics. Work in innovative information technology spans the spectrum from software systems designed to aid the health professional to network development linking Oregon Health Sciences University and Japan.

School Of Nursing

The School of Nursing is committed to the missions of the University. The primary mission of the School is the acquisition and distribution of knowledge relevant to the practice of nursing. The School of Nursing has gained a reputation for sound and innovative programs in education and research and attracts and retains highly qualified

faculty. Of the 108 full and part-time faculty at the School, 46% are doctorally prepared. The School was awarded accreditation for eight years by the National League for Nursing in 1987.

The School has an undergraduate program for both generic and RN students and a graduate program with master's and PhD components. The School offers an undergraduate nursing program through Eastern Oregon State College in La Grande. Additionally, La Grande coordinated a Rural Frontier Outreach program for place-bound generic students in Eastern Oregon. The RN-BS Educational Advancement program includes Salem, Eugene, Corvallis, and Newport. The master's component of the graduate program also rotates to outreach sites in various locations in the state on a predetermined schedule. Enrollment on the School of Nursing consists of 146 full-time and part-time master's students, and 45 doctoral students, 92 outreach students, 35 RN students and 360 generic undergraduate students. The structure of the School of Nursing is organized around areas of nursing knowledge and includes four academic departments: Adult Health and Illness, Community Health Care Systems, Family Nursing, and Mental Health Nursing, and one research support unit, the Office of Research Development and Utilization (ORDU).

Biomedical Information Communication Center

The Biomedical Information Communication Center was created to provide health care professionals throughout the state of Oregon with access to the medical information they need. The center's goal is to support the provision of topnotch, cost-effective health care in Oregon by making information technology available to all who contribute to the health of its citizens. The BICC is a new venture in biomedical information handling which consolidates the activities of the health sciences library, academic computing, biomedical communications, telecommunications, and medical informatics research.

The computing environment at OHSU offers a number of mini-computers (Hewlett Packard, Sun, Sequent) and 1200 microcomputers. A campus-wide StarLan network is in operation throughout the campus, allowing transfer of information by users on a variety of platforms: DOS, Macintosh, and Sun. OHSU is on an AT&T System 85 telephone system and dual voice/data jacks are installed in each office on the campus, allowing a microcomputer in each office to connect to the network.

The OHSU Library has a collection of 106,000 volumes; 68,000 monographs of which over 3400 are nursing texts; subscriptions and continuations to 2000 medical, dental and nursing journals, 80 of which are nursing journals. Services offered include reference services, database searching, interlibrary loans, a photocopy service, and training classes. These library holdings are further augmented by a reciprocal borrowing agreement among the Oregon State System of Higher Education Libraries which permits access to any student or faculty within the state system. Other reciprocal borrowing agreements with private institutions in the Portland area have also been negotiated.

A public access microcomputer area has machines available for use by students, faculty and staff. Training courses are offered year-round for popular software products such as Wordperfect, Excel, and Lotus 1-2-3 as well as basic introductory courses on computer use. Courses on enduser searching of health sciences databases are also available.

The BICC building is the OHSU Ed-Net site. As the state telecommunications project for training and education, Ed-Net is developing satellite teleconference capabilities between Oregon teaching sites. This will allow live interactive conferences between health care providers and educators at OHSU and their colleagues throughout the state.

ORHION (Oregon Health Information Online) is the BICC's electronic information service, to help fulfill its outreach goal. ORHION is available by subscription to health professionals throughout the state and currently includes OHSU

INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

Medline, a Medline subset; the OHSU Library online catalog; a photocopy request service; and a library request service. Other services will be added in the future, including the Cumulative Index to Nursing and Allied Health Literature as a new front-end search program.

The BICC is one of five IAIMS (Integrated Academic Information Management System) sites in the United States. A program of the National Library of Medicine, IAIMS aims to integrate information system on a university campus to allow faculty and students access to a variety of information services.

Center for Ethics in Health Care

A key setting for Lucia's training program will be the OHSU Center for Ethics in Health Care. The Center was established in July, 1989 as an interdisciplinary University-wide program whose mission is to facilitate education and research in health care ethics. Members represent health care administration, nursing, dentistry, medicine, dental hygiene, chaplaincy, law, philosophy, and social work. The Center focuses on innovative projects designed to improve health professionals' skills by identifying, analyzing, and resolving ethical issues in clinical care and health policy. The Center encourages the conduct of interdisciplinary empirical ethics research by promoting networking among research investigators, critiquing proposals, and providing assistance with grant applications.

Four organized task forces implement many of the Center's programs and activities. These are the Ethics Education Task Force, the Health Policy Task Force, the Ethics Research Task Force, and the Practice Task Force. The Ethics Education Task Force coordinates seminars which bring nationally and regionally known ethicists to the OHSU campus. Through its subcommittees, the Ethics Education Task Force promotes a bioethics study group, the Kinsman ethics in health care lecture series, an ethics reading group, the interdisciplinary ethics education program, and a speakers bureau. The Health Policy Task Force tracks state and federal policy and legal decisions in order to analyze and communicate the implications of policy change in these levels. The Ethics Research Task Force meets monthly with investigators to assist in the development of ethics research proposals and studies in all stages. Thirteen proposals were heard by this task force during the past year. The Practice Task Force has provided guidance in developing the first OHSU Ethics Consult Service. The Center has participated in the training of nine faculty in completing the Ethics Certificate Program at the University of Washington in Seattle. Both sponsors of the proposed training program, Drs. Tilden and Merkens have completed the certificate program. The Practice Task Force has been asked to respond to policy issues at the University Hospitals and will pursue this area of involvement in the coming year.

Susan Tolle, M.D., a board-certified internist with advanced training in clinical ethics, is the Center's Director. Michael Garland, D.Sc.Rel., has advanced degrees in both philosophy and religious studies and is the Center's Associate Director.

University Office of Research Services (ORS)

The Office of Research Services (ORS) for the Oregon Health Sciences University serves the functions of a grants and contracts office. ORS staff provide support for grant development in: 1) identifying funding sources, both private and governmental; 2) assisting in development of the budget; and 3) facilitating human subjects review. In addition, ORS supports funded projects through ongoing budget monitoring, interpreting of funding agency rules and regulations, and assisting in the preparation of progress/final reports. Also, the ORS periodically offers workshops on grant writing and grants management. The ORS is a valuable resource in both the development and ongoing management of all grants and contracts.

INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGENAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

School of Nursing Office of Research Development and Utilization (ORU)

The Office of Research Development and Utilization (ORU) in the School of Nursing, Oregon Health Sciences University, has a staff consisting of 1.25 FTE senior research consultants, 2.0 FTE research associates and 1.0 FTE support personnel and various work study students and graduate research assistants. The primary responsibility of these personnel is to facilitate the research of the faculty and of the nursing staff at the University Hospitals. The senior staff consultants provide expertise in a variety of areas, including quantitative research design and methodology, qualitative research design and methodology, measurement, and utilization of research outcomes in practice. The ORU staff provide a wide range of services including, but not limited to, 1) consultation regarding research development and implementation, 2) assistance with data processing including data entry and consultation on programming and interpretation of results, 3) back-up secretarial services, 4) research assistant services including data collection and coding, and 5) information services regarding funding sources and publishers.

In spring, 1992, the School of Nursing moved into its new 75,658 square foot building. ORU has 6840 square feet of space that has been specially designed to optimize the research requirements of the faculty and students. Included in this space are 2 wet labs totalling 640 square feet, a sleep lab that is 411 square feet in size; and a 295 square foot observational lab. There is a data processing lab which is fully equipped with state of the art equipment. Additionally there are 1711 square feet of space designed to accommodate funded research projects.

ORU has administered the allocation of funds from the Biomedical Research Support Grant (BRSG). These funds have been used primarily to support pilot research. Of high priority have been preliminary investigations in areas which hold potential for developing a significant program of research and for acquiring subsequent funding from either federal or private resources. The major objectives have been to: 1) support practice-relevant nursing research; and 2) foster development of methodological research to support innovations in measurement, design and analysis for a practice discipline. There is an opportunity for doctoral students to participate in these projects through monies available for research assistantships.

Computer Equipment

The School of Nursing has access to a minicomputer system--the Harris HCX. The HCX has a multi-use operating system with capabilities of interactive, batch and real-time processing. Video display terminals and PC's are used as input devices and are located in each department of the school. Most of the School's work is done on MS-DOS machines (XTs and ATs). All classified staff members and nearly all faculty members have a system at their desk or in their office. The two graduate student lounges have MS-DOS compatible machines for student use.

ORU has 5 MS-DOS XT machines, 5 286 AT machines and 2 386 machines for data processing and analysis. Available statistical software includes BMDP, SPSS-PC+, LISREL, and CRUNCH. ETHNOGRAPH is available for the analysis of qualitative data. For graphic support, ORU uses Macintosh equipment: 1 Mac II cx, 1 Mac SE30, 1 Mac SE, and 3 Mac Plus machines.

The University has five computer labs, one for open student use located in the Health Sciences Library (16 MacSE machines, 12 286 MS-DOS compatible machines). The laboratory is staffed with individuals able to provide basic assistance in data processing. There are also 4 satellite labs located in the basement of Emma Jones Hall (1 Mac SE and 1 XT), the basement of MacKenzie Hall (1 MacSE and 1 XT), the Basic Sciences Building (2 ARC 286 machines and 2 MacSEs), and the Dental School (1 XT and 1 MacSE). There are also two computer training labs, one located in Gaines Hall (12 AT machines) and a smaller one in MacKenzie Hall (6 AT machines).

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INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (Last, first, middle initial)

Wocial, Lucia D.

Library

The Oregon Health Sciences University Library serves as the information center for the Schools of Nursing, Medicine and other Oregon health professionals. There also is a branch library in the School of Dentistry. The main library houses over 180,000 volumes and subscribes to more than 2,000 periodicals and continuations. The book collection numbers approximately 55,000 volumes, of which over 3,400 are nursing texts. There are 76 journal holdings in nursing. In addition, the dental branch library contains 16,270 volumes and 350 journal holdings. These library holdings are further augmented by a reciprocal borrowing agreement among the Oregon State System of Higher Education Libraries, which permits access to any student or faculty within the state system. The library has also negotiated several other reciprocal borrowing agreements with private institutions in the Portland area for the same purpose.

OHSU is among five sites nationally chosen for the development of a national prototype for the Biomedical Library of the 21st Century. A federal appropriation of \$20.4 million to create the new facility, was completed in 1991. The University's existing library will be expanded by 50,000 square feet, its compatibility with existing computer systems will be assured and a Biomedical Information Communication Center (BICC) will be created to utilize new technology in information transfer. The "library of the future" will be designed not only to enhance information access by faculty and students, but also to provide for computer teleconferencing between health professionals in the Pacific Northwest and campus specialists. It will expand options for continuing education in the health professions and encourage exploration into new teaching methods and new communication techniques. The BICC will transform the library from a repository for the University collection to an interactive information transfer and management system.

Clinical Resources

The two University Hospitals on the OHSU campus have over 341 beds. They are leading acute care teaching hospitals in the State. Only about 50% of the hospitals' patients live in the Portland metropolitan area and nearly half come from throughout Oregon and SW Washington. Approximately 400 patient deaths occur in University Hospitals per year.

34. Number of fellows/trainees to be supervised during the fellowship.

Predoctoral

Anne Rosenfeld (NRSA predoctoral fellow); sponsor and dissertation advisor
Nita Ferreira (dissertation committee member)
Sheila Goodwin (sponsor of predoctoral individual NRSA application in preparation)
Dan Sheridan (sponsor of predoctoral individual NRSA application in preparation)

Postdoctoral

Sophia Harrell (Institutional NRSA postdoctoral fellow; 2/1/91 - 1/31/93)
Anne Hirsch (Institutional NRSA postdoctoral fellow; 6/1/92 - 5/31/94)

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INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

35. Applicant's qualifications and potential for a research career.

I have known Lucia Wocial since the early 1980s when she was a baccalaureate student in courses I taught at that time. Lucia distinguished herself from her classmates because she was brighter and more academically oriented than most and because she was interested in scholarship in nursing. She was articulate and she displayed an inquiring mind by seeking empirical evidence and challenging assumptions, and she earned a reputation as a thinker and a leader. As a result, Lucia was awarded the Oregon Nurses' Association Student Nurse of the Year Award. Now, almost 10 years later, Lucia continues to stand ahead of her classmates, which consist now of master's degree students. Based on the strength of her masters program application and her career goals, Lucia was accepted into the School's MS-PhD track, an honor awarded to few master's program applicants. She has accomplished most of the MS degree requirements in one academic year, which is a fast pace, and she has organized her master's work so as to lead directly into the PhD program and into her career goals of becoming a change agent in NICU nursing. Throughout her year of master's level study, Lucia has displayed the same thirst for knowledge, love of scholarship, and inquiring mind that she displayed at the beginning of her nursing career. Her thinking and writing skills are outstanding, and she is a disciplined worker who charts a course and stays with it to completion. In addition, she has added a commitment to a substantive nursing area of focus, that of neonatal intensive care nursing and clinical ethics. Her clinical staff nurse experiences in several NICUs has led her to know first hand the many complex ethical dilemmas for providers and families that arise in those settings. She is committed to gaining the research training necessary to mount a program of research that will lead to guidance for providers in navigating those dilemmas and improving outcomes for families. I believe she has the necessary capacity, the motivation, and the opportunity, through OHSU's rigorous research training program combined with our Center for Ethics in Health Care, to be successful.

36. Human Subjects/Vertebrate Animals/Hazardous Materials and Procedures.

The proposed research involves human subjects and no exemptions are claimed.

1. This proposed study focuses on parents of imperiled infants and their infants' care providers. At this stage in the development of the proposal, it is not possible to anticipate the number of subjects. The criteria used for inclusion in the study is the health status of an infant. Once an infant is identified as meeting criteria for the study, that infant's parents and care providers will be identified as potential subjects. Some anticipated characteristics for subjects include: a) age, 14-45 years; b) sex, male and female; c) ethnic background, Caucasian, Afro-american, Hispanic, Asian, or Native American; d) health status, good physical and mental health. Subject's involvement will consist of participation in an interview and being observed by the primary investigator during their interactions with infants.
2. Research data will be obtained from each subject for the purposes of this study. Data include transcripts from interviews and previously existing data from medical records.
3. Parents whose infant has been identified as imperiled by the primary investigator, primary physician or primary nurse, and whose primary physician has given consent for participation in the study, will be approached about participation in the study. Care providers for infants whose parents have consented to participate in the study will also be approached about participating. The primary investigator will provide subjects with oral and written information about the nature and purposes of the study. Oral and written consent will be obtained from each subject. Preliminary information has been submitted to the Oregon Health Sciences University Committee on Human Research for approval.
4. Potential risks for parents include psychological discomfort related to the stress of discussing their infants' condition and their feelings about it, and a potential alteration in the relationship they have established with their infants' care providers. The risk is of moderate seriousness and low probability. Potential risks for care providers are the same as the risks for parents.
5. Psychological discomfort can be minimized or prevented by ensuring that subjects' are interviewed in

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INDIVIDUAL NRSA APPLICATION
CONTINUATION PAGE

NAME OF APPLICANT (*Last, first, middle initial*)

Wocial, Lucia D.

private. Subjects will be reminded of the confidentiality of responses to questions and of their right to refuse to answer any questions and withdraw for the study at any time. If discomfort occurs, subjects will be referred to their personal physician and the Hospital Patient Advocate for counseling. A data coding system will be used to track units of data. Names and other identifying information will never be connected with the data. Data will be stored in a locked office accessible only to the researcher. The coding key that connects patient-case names to names, addresses and telephone numbers of family members will be stored separately in a locked file. Tapes of interviews will be erased and all data and coding keys will be destroyed at the conclusion of the study. No names of study participants, agencies or providers will be mentioned in any publications that disseminate study findings. It is felt that these methods for protecting against potential risks will be effective.

6. The potential risks to subjects are outweighed by the anticipated benefits. This study should advance scientific knowledge by providing empirical data about the experience of families with withholding and withdrawing treatment from infants in the NICU. These data could provide the basis for nursing intervention that will reduce stress related to the experience of families in these circumstances.

Vertebrate Animals: N/A

Hazardous Materials: N/A

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**INDIVIDUAL NRSA APPLICATION - CONTINUED
CHECKLIST (Front)**

NAME OF APPLICANT (Last, first, middle initial)

Wocial, Lucia D.

Applicant completes Section I (front). Sponsor completes Section II (back). Attach this checklist to the original copy of application.

Section I - Applicant

A. TYPE OF APPLICATION

- NEW application. (This application is being submitted to the PHS for the first time.)
- COMPETING CONTINUATION of award number _____ (This application is to extend a funded award beyond its current award period.)
- REVISION of application number _____ (This application replaces a prior unfunded version of a new or competing continuation application.)

B. ASSURANCES

1. DEBARMENT AND SUSPENSION No Yes (If "Yes," attach explanation.)

Before a fellowship award can be made, the individual signing this award application in Item 15, "Applicant Certification and Acceptance," on the face page must certify that, to the best of his or her knowledge and belief, he or she:

- (a) is not presently debarred, suspended, proposed for debarment, declared ineligible, or voluntarily excluded from covered transactions by any Federal department or agency;
- (b) has not within a 3-year period preceding this application been convicted of or had a civil judgment rendered against him or her for commission of fraud or a criminal offense in connection with obtaining, attempting to obtain, or performing a public (Federal, State, or local) transaction or contract under a public transaction; violation of Federal or State antitrust statutes or commission of embezzlement, theft, forgery, bribery, falsification or destruction of records, making false statements, or receiving stolen property;
- (c) is not presently indicted or otherwise criminally or civilly charged by a governmental entity (Federal, State, or local) with commission of any of the offenses enumerated in (b) above; and
- (d) has not within a 3-year period preceding this application had one or more public transactions (Federal, State, or local) terminated for cause or default.

If the individual is unable to make the required certifications, the individual should sign the application in Item 15 on the face page and attach an explanation to this Checklist page. The explanation will be considered in connection with the PHS funding component's determination to make the award.

2. DRUG-FREE WORKPLACE Yes No (If "No," attach explanation.)

Before a fellowship award can be made, the individual signing this award application in Item 15, "Applicant Certification and Acceptance," must certify that, as a condition of the award, he or she will not engage in the unlawful manufacture, distribution, dispensing, possession, or use of a controlled substance in conducting any activity under the award.

If the individual is unable to make the required certification, the individual should sign the application in Item 15 on the face page and attach an explanation to this Checklist page. The explanation will be considered in connection with the PHS funding component's determination to make the award.

C. NRSA SENIOR FELLOWSHIP APPLICANTS ONLY

1. PRESENT INSTITUTIONAL BASE SALARY

Amount _____ Academic period/number of months _____

2. STIPEND/SALARY DURING FIRST YEAR OF PROPOSED FELLOWSHIP

a. Stipend requested from PHS:

Amount _____ Number of months _____

b. Supplementation from other sources:

Amount _____ Number of months _____ Type (sabbatical leave, salary, etc.) _____ Source _____

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Advocacy In Action
Lucia D. Wocail, RNC

Advocacy In Action

It is easy to get caught up in providing critical care to infants and supporting their families and think, what does theory have to do with clinical practice? More and more words like theory, concept and research are creeping into nursing literature. For many of us, theory was something we had to know to get through school, but it was not always clear what it had to do with clinical practice. To be a good clinician today requires more than good clinical skills. It requires a good understanding of nursing as a science and a profession.

Theory is defined as "a set of concepts, definitions, and propositions that projects a systematic view of a phenomena by designating interrelationships among concepts for purposes of describing, explaining, and predicting phenomena".¹ Simply stated, a theory is a structuring of ideas and concepts. A concept is nothing more than an abstraction of reality, usually derived from individual experience.²

The value of physiological theories to clinical practice is not hard to accept because these theories are grounded in the reality of human bodily functions which as nurses we constantly monitor and record. But sometimes the relevance of more abstract theories and concepts is hard to comprehend. Consider however that significant experiences serve as opportunities to solidify the meaning of an abstract concept. Examples from clinical practice provide a rich source of information and a good foundation for identifying and clarifying abstract concepts in nursing. Current literature uses the term paradigm to represent an example.³ A paradigm is an expression of theory, knowledge and processes for knowing.² A paradigm in its most basic form is an example.

Identifying concepts in nursing is a complex and intricate endeavor. Even the simplest idea becomes complicated when one attempts to define the concepts

involved. The purpose of this article is to take the events of a paradigm case from clinical practice, isolate a nursing concept, define the critical attributes of the concept and analyze it in depth to show the importance of applying it in clinical practice. Only after reflection over time on the events of this paradigm case did the essential nursing concept become clear. Understanding the less tangible concepts and ideals of nursing provides greater insight into the nuances of providing bedside care and contributes to the development of expert clinical practice.

Paradigm Case

TJ was a 34 week gestation premature black baby girl. She was transferred to the neonatal intensive care unit (NICU) for evaluation of multiple congenital anomalies. She had situs inversus, dextrocardia, AV canal and multiple jejunal atresias. The baby's mother, who tested positive for HIV was in prison for prostitution and drugs. Her only contact with the infant was via telephone

Shortly after birth TJ underwent surgery to correct her intestinal blockage. Because of her multiple problems surgeons, cardiologists and neonatologists were all involved in her care but the surgical team had primary responsibility for her plan of care.. As TJ's primary nurse, I read all the available information on her anomalies and wondered about her long-term prognosis. I shared some of the information I had read with the surgeons and expressed concern about TJ's prognosis and the aggressiveness of her treatment. The surgeons suggested that I wanted to "give up" on the baby because she had positive HIV antibody titers. I denied this accusation and suggested to other members of the health care team that we discuss long-term goals and treatment options for TJ. The surgical team responded that they would fix her surgical problems and deal with her other problems individually as her condition improved.

TJ tolerated the surgery well, however post-op she developed heart failure. The cardiologists suspected her failure was secondary to her AV canal and felt this reflected poorly on her overall prognosis. Her condition did not deteriorate, but she made no significant improvement over the next four weeks.

I think it is important to mention that I felt very strongly that we, as a health care team were not being realistic about our expectations of recovery for TJ. There was no consensus about her long-term prognosis and no open discussion about the lack of consensus. At the time, I did not have a clear idea about what to do to resolve the situation. I now know that a patient care conference including all the health care providers involved in TJ's care would have been helpful at this time.

After four weeks of stability TJ experienced a sudden rapid deterioration. When I started caring for TJ one morning she had a serum glucose greater than 200, her resting heart rate was less than 90 and she was unresponsive. When I checked her blood pressure it was 35/22 with a mean of 28. I paged the surgical team because I felt the baby was at risk for a cardiac arrest. By the time I returned to her bedside my fears were realized.

After three hours of resuscitation and stabilization efforts, TJ required full ventilatory support with 100% oxygen, paralytics to manage her respiratory status and several pressor drips to maintain her blood pressure. The neonatologists who assisted the surgeons with the code expressed pessimism about the baby's chances for survival.

We notified the baby's mother and made arrangements for her to visit. Later that day she arrived in shackles, accompanied by guards. The surgeons attempted to explain what happened but during their discussion the baby again required resuscitation efforts.

The resuscitation efforts were successful. After the baby was again stable I asked the other members of the health care team, if they would talk to the mother about the possibility of the baby not surviving. The surgeons adamantly stated that they could not just turn the baby off now that the mother was there and explained that they would begin to address her other problems once she was stable. At that time, no other member of the health care team voiced concerns similar to mine.

Before the baby's mother left the NICU the surgeons spoke with her. I was present for the discussion. There were no other doctors from the health care team present. Knowing that no physician on the health care team shared my concerns made me feel awkward and restricted in my role. The surgeons explained to the mother that the infant was very sick. They did not at any time mention the possibility that the baby might die. They were in fact cautiously optimistic about her chances.

When the surgeons left, TJ's mother asked me if I thought the baby was in pain and if I thought her baby would die. I truly believed that the baby would not benefit from further efforts and I was afraid that this would be the last time her mother would see her. I chose my words carefully and told TJ's mother that I thought the baby was not in pain because we had given her medicine for that. I also said very clearly that as TJ's nurse, I worried that there might come a time when we would not be able to help her any more and that we would only be hurting her if we continued. The mother reached out to stroke the infant's hand and stated that she hoped we could fix her baby.

Several other nurses from the NICU later approached me to tell me how much they admired me for speaking up, even though my words seemed to fall on deaf ears. Most of them stated that they felt the way that I did, that we were just

prolonging the inevitable, but that they did not feel they could speak up. Their support helped strengthen my conviction to speak up.

TJ remained on maximum support for two weeks. In that time the surgical team transferred primary responsibility to the neonatology team. The neonatologists were pessimistic about TJJ's chances for recovery and began to approach the mother about withdrawing treatment. Telephone calls provided the only contact between the mother and health care team. Her phone calls were limited in number and length by prison officials.

The attending neonatologist kept talking about how stable the baby's cardiac status had become. The mother resisted withdrawing treatment citing the doctor's references to TJ's improved cardiac status. One day when the attending physician was on the phone to the mother, frustration at my own inability to get other members of the health care team to look at the whole picture came to a head. In the middle of the conversation I said to the doctor, who was talking to the mother, "tell her about what frequent episodes of hypoxia does to the brain!" I then shrank away, horrified that I had blurted that out, especially since she was trying to speak to the mother.

I expected to be blasted for my behavior. When the neonatologist finished the phone call, before she could say anything to me I apologized not for what I said but for how I said it. She surprised me when she looked at me and stated that she had never thought of presenting the situation to the mother that way and once she did, the mother realized the severity of TJ's condition and agreed to stop treatment.

We arranged for TJ's mother to come to the NICU. When her family arrived we took them to the room where she waited. Once all TJ's family was prepared I returned to her bedside. I had bathed her and dressed her. With the doctor in attendance, I carefully began disconnecting TJ from all her IV drips and finally

extubated her. I carefully wrapped the baby in a blanket. We walked to the room where TJ's family waited. I placed TJ in her mother's arms for only the second time in her life. After only 27 minutes TJ's heart stopped beating.

This episode had a profound impact on my career. As a bedside nurse I frequently felt frustrated at my lack of contribution to developing the overall plan of care. I felt a part of the whole team as long as I did not wish to discuss uncomfortable topics or did not disagree with physicians. By this point in my practice I had seen several cases where the nurses felt the doctors were refusing to "see the writing on the wall" and stop heroic efforts to save a life. I had seen families pin their hopes on the smallest chance of recovery because doctors would not discuss the possibility that their infant might die and nurses would not or could not discuss the unsayable with them. In this case I was determined to be a voice that would be heard. I wanted to be an advocate for TJ.

I have reflected often on this case over the years. As I have gained experience in neonatal intensive care and collaboration with other health care team members I can see where I as a TJ's nurse could have been a better advocate for TJ and her family. After careful examination of this paradigm, I realize that believing I was acting as an advocate for TJ is what enabled me to be persistent and speak up in what was for me a tough situation.

I think that if I had better understood the abstract concept of advocacy when I was caring for TJ I would have been able to identify the problems we as a health care team were having in communicating with each other and ultimately in providing care for TJ. Advocacy has become for me the essence of nursing. It is the most powerful intervention nurses can perform. It is an abstract and complex concept, but one well worth exploration.

Concept Identification

This clinical situation is filled with concepts. As a paradigm it provides a wonderful opportunity to make an abstract concept more concrete. Identifying the one concept that captures the deep meaning of this paradigm case poses an immense challenge. The task is to find the one word that conjures up an image which conveys the essential idea behind the concept.² Advocacy first comes to mind but that one word does not capture the whole meaning of the concept. The words that come to mind for this case are active advocacy. The concept active advocacy provides a label for actions the nurse performed in this situation but also conveys some meaning about the motivation.

To be active is to perform actions, and also refers to the power to exert influence.⁴ Both these definitions apply to how active is used in the concept active advocacy. Defining advocacy is a little more complex. Webster defines advocacy as the act of pleading for, performing intercession or mediation.⁴ Under advocacy the thesaurus lists several words with similar meaning including the act of advising, defending, urging and supporting.⁵ All of these words have positive meaning. They create an image of someone doing something positive to help or assist someone else.

The common meaning for advocacy is the legal one, that of defending as in vindication. The AIDS epidemic has given the word a more powerful meaning for many people. Advocacy in relation to AIDS creates an image of someone fighting for a cause; a spokesperson for people unable to fight for their own cause. The meaning associated with the phrase devil's advocate creates a somewhat contrary meaning for advocacy. This phrase implies an argumentative quality to the concept of advocacy.

The several meanings of advocacy in everyday language underscore the lack of consensus about the meaning. The definition of active advocacy cannot be clearly

stated in a few words. It is a combination of all of the meanings of advocacy and the meaning of action. Active advocacy is being a persistent advocat. Many patients, especially infants are unable to speak for themselves and therefore require a spokesperson. Intercessions for infants must be motivated from thinking of their best interests. Sometimes, as in the paradigm case, being an advocate means arguing against the mainstream of ideas. Even though no definition for active advocacy exists in nursing literature, the many definitions of advocacy found there contribute to the meaning of this concept.

Advocacy in the Literature

The concept of advocacy discussed in the nursing literature is similar to the concept of active advocacy. Theoretical works make up the bulk of nursing literature on advocacy. Current authors often cite Curtin's work as a philosophical foundation for advocacy in nursing.⁶ She defines advocacy as the precursor to forming any nurse patient relationship. She insists that nurses have special abilities to experience the patient as a human being and this knowledge enables them to perform in a human advocacy role. She lists providing information, working collaboratively with physicians and respecting the patient's decisions as primary responsibilities of human advocacy. She does not see human advocacy as something a nurse chooses to do. She believes it is the essence of what nurses do.

Several authors discuss the evolution of advocacy in nursing. Nelson believes the advocacy role in nursing now focuses on mediator, with emphasis on the coordination of services.⁷ In order to do this, nurses must concentrate on clear communication with patients. Corcoran views advocacy as helping patients to become informed decision makers.⁸ The crucial element in this perspective is patient autonomy. These perspectives of advocacy assume that patients can actively

participate in the advocacy interaction. Making this assumption when working with infants in an NICU poses obvious problems.

A research study by McKinley attempted to obtain data from critical care nurses regarding their feelings associated with performing an advocacy role for incompetent patients in their care.⁹ She defined the nurse-advocate as "a nurse who acts to defend or promote the best interests of the patient."⁹ This definition comes close to "active advocacy" because it specifies action by a nurse. However, it does not state how a nurse should act to accomplish advocacy.

The patients in the study were adults but their conditions prevented them from participating in decisions about their own care, a situation similar to what infants experience in an NICU. The study showed that using McKinley's definition for advocate, 50% of the participating nurses felt it was part of a nurses role to be an advocate for incompetent patients. The nurses most likely to feel this way had several years experience in critical care and had experienced similar situations often.

In her discussion of advocacy with silent patients Gadow illustrates another element of advocacy with direct application to infants in an NICU.¹⁰ She states that entering a patient's world through embodiment provides the avenue to subjectivity and this is essential to advocacy. What this means simply is that nurses must put themselves in their patients' shoes. Only by doing this can nurses begin to advocate for patients whose feelings are unknown. Advocacy in this instance then is based not on patient rights but on concern for patients' well being.

Discussions of advocacy in pediatric nursing require special attention. Penticuff describes the key to advocacy in pediatric nursing as involving the family.¹¹ Advocacy interventions in pediatrics focus on the family not the child patient. Parents in this case need to have information clarified, to participate in

planning care and to have support in their decisions. This approach would also work with parents of infants in an NICU.

Comparing and contrasting different definitions of advocacy as defined in the nursing literature reinforces one thing. Advocacy has broad meaning. It has meaning for actions as well as motivations for the actions. It is what Walker and Avant would call an umbrella term.¹² All of these views of advocacy are part of the definition of active advocacy and helpful in understanding its' complexity but none captures its essence. Perhaps providing some hypothetical case examples will make the defining attributes for the concept more apparent. With such a complex concept it might be easier to form a model case by first looking at cases that clearly do not represent the concept.

Case Examples

There are three hypothetical cases described below. The contrary case is an example where the concept active advocacy is not demonstrated. There are no critical attributes present. The borderline case is one where some of the critical attributes for active advocacy are present but not all and thus the concept is not clearly and distinctly represented. The final example is a model case. A model case is an example that demonstrates how all the critical attributes of active advocacy work together to define the concept.

Contrary Case

Parents of an infant transferred to the NICU arrive several hours after the infant. They approach their baby's nurse and explain that they don't understand what is going on and would like to have some questions answered. While they are speaking with the nurse, the mother constantly strokes the infant's head. The infant's oxygen requirements decrease during this interaction. The nurse, trying to finish her work before the change of shift, tells the parents that if they will wait in

the lounge area, she will page the neonatologist who will come and speak with them. She then ushers the parents out. She returns to complete her work and increases the infant's oxygen supply in response to a monitor alarm indicating low oxygen saturation. She passes on in report that the parents have been waiting in the lounge for the neonatologist for half an hour.

Clearly the nurse in this example has put her own needs ahead of her patient's and her patient's family's needs. She makes no attempt to provide information. She fails to assess the clinical change of the infant during the mother's intervention. She has failed to effectively communicate with any of the key people in the situation. There is no little evidence of active advocacy in this case example.

Borderline Case

Parents of an infant in the NICU talk with the neonatologist about their baby's prognosis. The neonatologist uses a lot of medical terms and finishes by saying that there is no way to know what will happen. The neonatologist and the nurse previously discussed the situation. They realize that the infant has a poor chance of surviving without long-term medical needs.

After the neonatologist leaves the nurse helps the parents understand all the medical terminology used by the neonatologist. The parents express their concern that their infant will have lots of problems in the future. The nurse supports the parents by allowing them to vent their fears but makes no attempt to communicate what she and the neonatologist realize. She also makes no attempt to involve the physician in the discussion.

In this example the nurse provides some positive support for the parents. She even makes attempts to clarify communication. But she fails to act. She fails to provide information that the parents clearly seek. By failing to validate what the parents suspect, she has failed to put herself into her patient's shoes and help the

parents understand the ramifications of what treatment means. One might argue that the nurse in this case performs partial or passive advocacy.

Model Case

A critically ill premature infant arrives in the NICU. The parents anxiously wait outside while the team stabilizes their baby. The nurse caring for the infant asks one of her colleagues to tell the parents they will be able to see their baby in 15 minutes and that the doctors and nurses will be able to talk with them then. She then focuses her attention on the infant. She carefully assesses the infant to determine necessary interventions to ensure the infant's safety and comfort needs are met.

The neonatologist confides in the nurse that the infant's chances for survival are poor. Once the parents arrive the nurse provides brief explanations about all the equipment attached to their baby. The parents are crying and want to know if everything will be ok. The doctor explains the seriousness of their baby's condition but does not discuss the possibility of the infant not surviving. The nurse then shares her concern for the infant's survival with the parents and asks the doctor to comment on his concerns for the infant's survival. The doctor and nurse reassure the parents that they will care for their baby as best they can and that they will help them in any way possible.

In this example the nurse acknowledges the family as a vital part of the care of her patient. She is persistent in her efforts to facilitate communication about the infant's condition and chance for survival. She demonstrates expert clinical skills working with the infant. She actively takes part in discussions about the baby's care through collaboration with the neonatologist. She demonstrates active advocacy from the moment the infant arrives in the NICU.

Concept Discussion

Before identifying the defining attributes of active advocacy it is necessary to look at the concept using different contexts and values. In the model cases above clearly the needs of the patient and family have great value. If this situation took place in a culture that placed high value on the whole of society not its individuals then focusing on the patient and family would not be appropriate. If the family in this situation believed strongly in the power of faith to heal and had no confidence in technology, again the focus for advocacy must shift to the well-being of the infant. In an extreme example, if treating the infant in the NICU meant that the family would starve, then the focus for advocacy might shift away from the infant to the family. These examples illustrate how different contexts and values affect the implementation of active advocacy.

The final step to accomplish before defining critical attributes for active advocacy is differentiating antecedents to and consequences of the concept. Antecedents are events or incidents that must be present for a concept to occur. Conversely, consequences are events or incidents that happen as a result of the concept.¹¹

Before nurses can perform active advocacy, they must possess certain characteristics. Because correct assessment and intervention are essential first steps to patient advocacy, nurses must have clinical expertise.¹⁴ Nurses must have confidence in their understanding of a situation. They must use effective communication skills and take responsibility for a patient's well-being by negotiating and helping to manage the health care team's' responses to patient situations.¹⁴ Nurses must have the patient's best interest in mind at all times. And finally, a nurse-patient relationship must exist for a nurse to practice active advocacy. In the NICU this means a relationship with the infant patient and that infant's family.

Some of the consequences of advocacy represent real deterrents to nurses who contemplate active advocacy. Taking on an active advocacy role for nurses means breaking away from the traditional obedient servant role which hospitals have reinforced for so long.¹⁵ It means being willing to speak up on a patient's behalf even in tough situations. It means taking on the responsibility for the patient's best interest. Perhaps the most concrete burden of advocacy stems from potential legal ramifications. Because the advocacy role is not clearly or uniformly defined in nurse-practice acts, nurses have no clear guidelines that show when advocacy ends and inappropriate intervention begins.⁷ The most practical way to summarize the concept of active advocacy is to list its critical attributes.

Concept Summary

Assuming that all the antecedents mentioned above exist, the most critical attribute of active advocacy is action. Active advocacy requires that nurses do something, speaking up for example. The drama of the ethical dilemma in the paradigm case draws attention away from the interventions that define active advocacy. An ethical dilemma is not necessary for active advocacy to take place. However, ethical dilemmas are perhaps the ultimate test of active advocacy.

The critical actions for active advocacy in the NICU include facilitating information exchange between all the parties involved in caring for an infant, verifying the accuracy and completeness of the information exchange, participating actively in the decision making process regarding the plan of care and providing support to the patient and family regardless of the decision chosen. Active advocacy is not a one time intervention nor is it a one person intervention. It is a series of ongoing interventions that must begin on admission. For active advocacy interventions to be most effective, they require constant evaluation and adjustment from all members of the health care team.

Describing empirical referents for the above actions will help to make the concept of active advocacy more concrete. In the paradigm case the nurse missed several opportunities to facilitate communication and information exchange. An example from the paradigm case where the nurse did facilitate information exchange is when she provided the neonatologist with a different perspective of the infant's prognosis. A more effective way to facilitate information exchange would be to request a patient care conference.

The only way to verify the accuracy of the exchanged information is to actually ask each person, did you understand what was discussed, or can you tell me in your own words what was said? And then to document the responses. The only way to verify completeness is for each person involved in the process to bring a list of information they feel is essential to discuss and to check off each item from the list once it has been discussed. There are no clear examples of verification of accuracy or completeness of information exchange from the paradigm case.

In the paradigm case, the nurse's ability to anticipate potential events demonstrates clinical expertise.. Doing nursing care for an infant on maximum life support is an obvious example of providing physical support to the infant patient. The empirical referents for supporting family come in the form of emotional as well as physical support. Bringing the mother of TJ to the NICU to see her and hold her while she died was a way to provide both physical and emotional support.

Implications for Practice

In NICUs nurses face a unique and difficult challenge when they attempt to implement active advocacy. Taking part in the decision making process regarding planning care means not only ensuring that the nursing perspective is represented but also that the patient's perspective is represented. Once nurses gain confidence in their abilities, they must use their clinical expertise, put themselves in their

patient's place, and use effective communication skills to share that perspective with the other people involved in the infant's care.

Nurses, because of the intimacy of the care they provides, are the best people to estimate the patient's perspective and to implement active advocacy on their patient's behalf. The challenge in doing this is that clinical experience brings a level of subjectivity to anyone's perspective. To be effective advocates, nurses must strive to be objective which means performing a delicate balancing act weighing their judgement and subjectivity against objectivity and the patient's best interests.

Implications for Research and Clinical Practice

From this discussion it is clear that active advocacy is only one level of advocacy. One of the most important research questions to address related to this concept is discovering what patients and families feel are the essential attributes to advocacy and whether or not they perceive a need for nurses to perform this role. Parents may be advocates for their infants but nurses' special skills allow them to practice active advocacy as described in this article. A Better understanding of active advocacy can be achieved through research. Understanding this concept better will improve NICU nurses' clinical practice. If as suggested earlier, ethical dilemmas are the ultimate test for active advocacy, then it is vital to determine if nurses' practice role in ethical decision making in the NICU includes practicing active advocacy. This is one example of where research can lead to improved clinical practice.

Summary

Any experience from clinical practice can become a paradigm case. Identifying active advocacy as a critical concept did not happen until I had spent time reflecting on the events of this case. Even though this case lacks all the critical attributes of active advocacy it has helped to clarify what attributes are critical to the concept. It has helped to make an abstract concept more concrete. The paradigm also provides

a forum for illustrating the importance of applying an abstract concept to clinical practice. Enabling nurses to utilize the concept in practice begins with research about the concept and continues by sharing information from research.

Nurses in clinical practice face two challenges. The first is to explore complex abstract concepts in their everyday practice. The second challenge relates to their unique knowledge as clinicians. Nurses who provide bedside care have a rich source of knowledge gained through their experiences. This paper has demonstrated how nurses in clinical practice can relate their own paradigms to other nurses. Sharing information and experiences is a way to improve the profession of nursing and increase the body of knowledge that makes up the science of nursing.

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Appendix B
Letter of Acceptance to
Doctoral Program



OREGON HEALTH SCIENCES UNIVERSITY

3181 S.W. Sam Jackson Park Road, L109A
Portland, Oregon 97201-3098 (503) 494-7800

*Schools of Medicine and Nursing
Office of Admissions and Registrar*

April 12, 1991

Lucia Wocial
3198 Kimber Court #96
San Jose, California 95124

Dear Ms. Wocial:

The Oregon Health Sciences University School of Nursing is pleased to offer you admission as a graduate student in the M.S./Ph.D., Department of Family Nursing, beginning September 26, 1991. Orientation will take place on September 20th and classes will begin on the following Thursday.

If you have not already responded to this offer by calling Kristen Thomson, please do so immediately by calling (503)494-7893.

If you decide to accept this offer and have questions concerning financial aid, you should direct an inquiry to the Office of Student Financial Aid, L109, at the Oregon Health Sciences University or call 494-8249.

If you decide to accept this offer, it will be necessary to submit by May 15, 1991, a non-refundable class reservation deposit of \$100.00 which will be applied toward Fall 1991 tuition.

You will be receiving additional correspondence from this office during spring quarter; and may I personally congratulate you on your acceptance.

Respectfully,

A handwritten signature in cursive script, appearing to read "Dick B. Speight".

Dick B. Speight
Director of Admissions
and Registrar

DBS:cds
enclosure