NURSES WITH DISABILITIES:

A PHENOMENOLOGICAL STUDY OF NURSES WHO ARE BLIND

By

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To the faculty of Washington State University:

The members of the Committee appointed to examine the thesis of SARAH MAUREEN BUTTRELL find it satisfactory and recommend that it be accepted.

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Chair

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NURSES WITH DISABILITIES: A PHENOMENOLOGICAL STUDY OF NURSES WHO ARE BLIND

Abstract

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The purpose of this study was to explore the experiences and role of blind nurses and nursing students in order to better understand the role of the blind nurse. The phenomenological method was used to research the lived experiences of four blind nurses recruited through purposive sampling. In addition to the study's phenomenological framework, the social model of disability theory guided the study.

Four participants were interviewed in individual one-on-one interviews via telephone and email. The participants described specific examples of their experiences as a blind nurse in nursing education and/or the nursing clinical workplace.

During the interview discussions, the following themes emerged: barriers to nurses with visual impairments, strategies to overcome barriers, role modeling as a minority nurse, safety concerns with visual impairment, and accommodations under the American with Disabilities Act (ADA). Conclusions include recommendations for culturally competent education and suggestions for workplace support.

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Dedication

This thesis is dedicated to the wonderful students at Washington State School for the Blind who inspired the question and drove me to look for the answer.

You have taught me so much.

CHAPTER ONE

Introduction

Nursing has been slow to clarify the role of nurses and nursing students with disabilities. The Americans with Disabilities Act has specified legal requirements to provide reasonable accommodations for disabled students and employees. Persons with disabilities applying for nursing school and nursing employment have caused schools and employers to scrutinize their philosophies and standards regarding nursing competencies and reasonable accommodations.

The purpose of this study was to explore the experiences and role of blind nurses and nursing students in order to better understand their roles. The phenomenological method was used to research the lived experiences of four blind nurses or nursing students recruited through purposive and snowball sampling. Heideggarian hermeneutics provided the conceptual guide for this study.

In an age of growing concern over the implications of the Americans with Disabilities Act of 1990 (ADA), schools of nursing have begun to open their doors to students with disabilities (Arndt, 2004; Black-Ney, 2004; Carroll, 2004). This has prompted debate and concern regarding the capabilities of nurses with disabilities. While articles regarding this topic tend to focus on a broad range of disabilities, this research study is focused on understanding the lived experiences of nurses and student nurses who are blind.

When nurse educators were given a list of disabilities to rank from most likely to succeed in nursing education to least likely, blind students were ranked the lowest (Sowers & Smith, 2004). However, contradicting a popular belief that it is impossible to

be a blind nurse, blind students have successfully graduated from nursing and other health professions and gone on to practice successfully ("Blind woman will pursue her dream of becoming a nurse," 2005).

Statement of Problem

Because of the nursing shortage, pressure from Americans with Disabilities Act lawsuits, and the need to diversify nursing education to reflect the cultural community, nurses with disabilities have been a popular topic of discussion in recent years within nursing journals. In an age where nursing is trying to diversify in order to represent the larger population in gender and ethnicity, nursing appears to struggle against the need to incorporate a broad range of abilities, regardless of the legal mandates which require equal opportunities for students and employees with disabilities (Arndt, 2004; Bohne, 2004; Carroll, 2004; McCleary-Jones,2005; Moore, 2004; Sowers & Smith, 2004).

Though there was persuasive literature urging nurses to hire, teach, and embrace students with disabilities (Arndt, 2004, Bohne 2004, Carroll, 2004), few research-based articles were found which indicate what support nurses with disabilities need or barriers they have faced. One study focused on assessing and changing nurse attitudes towards students with disabilities (Sowers & Smith, 2004), and another interviewed students with physical disabilities and their personal experiences in nursing education (Maheady, 1999). Additionally, an article described the experiences of a nursing instructor working with a nursing student who was in a wheelchair (Evans, 2005).

Though general information regarding the experiences of disabled nurses was found in the literature review, no research was found that focused on one specific

disability. To best understand the specific barriers persons with a particular disability might encounter, this researcher proposes that nursing research should focus on barriers confronting particular populations and the accommodations required. This type of research provides a resource for nursing students with disabilities, educators, nurses with disabilities, and employers who are working to provide accommodations.

None of the nursing disability literature included blind nurses. This void is likely a result of the small percentage of blind nurses. However, the small number of blind nurses raises additional questions: Are there reasons why a blind student would not choose to enter the nursing profession? What barriers exist? What resources exist to overcome these barriers? What strategies or accommodations are most supportive? Because of the lack of literature relating to blindness and nursing, it is apparent that the role of blind nurses is yet to be understood.

Statement of Purpose

The purpose of this study is to explore the lived experiences of blind nurses and student nurses. The goal of this study is to provide increased understanding regarding the experiences of this specific group of professionals and to determine whether or not barriers exist for blind students becoming nurses or for nurses to continue working after experiencing blindness. It was the researcher's goal to identify whether or not barriers exist and, if so, what might be done to decrease or eliminate these barriers.

Conceptual Guidance

Heideggerian phenomenology guided this research. The focus is "the relationship of the person to the world…world is the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture" (Leonard,

1989, p. 44). Phenomenology gives the researcher the philosophical framework that allows participants to describe and interpret their experiences based on their own understanding. Because of this, the narratives in stories and examples are considered the lived experiences and perspective of the participants.

Benner and Wrubel (1989) based their nursing research on the phenomenological idea that humans are formed by personal and cultural history. According to this philosophy, experiences shape who we have become and what meanings and concerns we have. The events and the culture that have influenced our lives create a connection and a focus of meaning which determine how we relate in the world. Background meaning "is that which determines what counts as real for that person. Background meaning is not itself a thing, it is rather a way of understanding the world" (Benner & Wrubel, 1989, p.46). Based on this philosophy, the importance of participants' experiences and meanings, as they relate to their role as blind nurses and nursing students, is vital to the core of the research.

The concept of storytelling as a way to communicate meaning and experiences was incorporated into this study. Phenomenology supports the use of specific stories and examples to get to the meanings that cannot be easily quantified but from which meanings can be drawn (Conroy, 2003). As opposed to scales and numerical data, stories can express foundational emotions and feelings. Stories can describe what it means to be human—to love, to hurt, to feel disappointment and rejection, and to find hope and success (Benner and Wrubel, 1989). The researcher embraces the practicality and meaning of recounting personal experiences because this type of research can create a sense of relationship and empathy between the readers and the

participants' experiences. Therefore, the researcher encouraged the participants to relate specific stories and experiences and used participant quotes liberally in the research findings.

Literature Review

Recent nursing literature has called for a cultural change in the way nursing views nurses and nursing students with disabilities (Arndt, 2004; Bohne, 2004; Carrol, 2004; Moore, 2004; Sowers & Smith, 2004). Moral and legal pressures have highlighted concern that society has created a sub-class out of disabled citizens (Marsh, 2005). The categorization of the disabled is also reflected in the nursing profession.

The following is a list of information found in the literature review of nursing and sociology journals. The search terms "blind nurses," "disabled nurses," and "nursing education AND students with disability" were searched in ProQuest, ProQuest Nursing Journals, Sociology Abstracts, MedLine, and Cinahl. Common topics covered in these articles were: the Americans with Disabilities Act, society's role, attitudes within nursing education and the workplace, and core competencies of nursing.

Americans with Disabilities Act. The Americans with Disabilities Act of 1990 (ADA) has put pressure on workplaces and educational institutions by giving disabled persons rights in their workplace and educational settings. According to the ADA, reasonable accommodations must be made for students with disabilities. Because "reasonable" is not a strictly defined word, there has been much confusion and debate regarding what is considered a "reasonable accommodation", especially in nursing education (McCleary-Jones, 2005). Many lawsuits and institutional policies since the 1990 passage of the ADA have helped define and implement reasonable

accommodations (Black-Ney, 2004). However, no simple solution to accommodate disabled nurses has been found (Bohne, 2004; McCleary Jones, 2004). A study looking at the inclusion of nursing students with disabilities indicated that, despite protections such as the ADA, discrimination towards disabled students still occurs within nursing education (Sowers & Smith, 2004).

Society's role. There was limited research on blind individuals' reflections on health care and society attitudes. However, a study focusing on the lived experiences of blind mothers highlighted some of the mothers' experiences with labor and delivery nurses. According to Shackleford (2004), participants stated that nurses they encountered in these units indicated through their actions that the blind mothers were unfit to care for their children. For example, a nurse would not allow one mother to be left alone with her baby. The mothers reported feeling that the nurses were ignorant of their abilities and instead focused on perceived limitations related to their blindness.

Nursing tends to use the medical model of disability—the goal is to fix the disability rather than see it as an integrated part of the person's holistic being (Moore, 2004). Viewpoints and attitudes of nurses, stemming from this model, have been hypothesized as possible reasons why students with disabilities are less likely to be integrated into nursing than other professions (Arndt, 2004). Students with disabilities may be treated by other nurses and nursing instructors as patients needing care rather than capable students and nurses.

The medical model has been critiqued and compared with the newer social model of disability. For instance, one disability researcher and critic of the medical model states, "the lived experiences of nursing students with disabilities illustrates a

limitation of the medical model as an approach to conceptualize the study" (Marks, 2000, p. 207). Marks explains that, in order to understand the experiences of persons with disabilities, the researcher must focus on their experiences rather than their disability.

Nursing Education and Workplace. Nursing instructor attitudes towards students with disabilities has been directly examined in research studies. One study measured the attitudes of nursing instructors towards accommodating students with disabilities (Black-Ney, 2004). Three hundred and seventeen nursing instructors from various nursing schools participated in a comparative descriptive study. The results of the study indicated that nursing instructors with higher levels of education were less discriminatory toward students with disabilities (Black-Ney, 2004). The study thus indicated that higher educational levels decrease attitudinal barriers towards students with disabilities.

Sowers and Smith (2004) studied 88 nursing instructors in eight different schools of nursing. These participants were involved in the comparative descriptive study assessing nursing instructor attitudes towards students with disabilities. While nursing instructors were found to have negative attitudes towards students with disabilities, it was also found that nursing instructors indicate a desire and need for further education regarding students with disabilities. A subsequent study by Sowers and Smith (2004) found that with educational training approaches, including personal experiences with disabled nurses, attitudes towards disabled students could be improved.

Research also demonstrates a discrepancy in employment and compensation for blind individuals. One non-nursing study found that higher education among the blind

population does not correlate with an increase in income as it does for their sighted counterparts. The researchers attributed one of the main problems with the low employment percentage of blind graduates to attitudes of employers in the workplace (Crudden, Sansing, &Butler, 2005).

Core Competencies of Nursing. The topic of inclusion of students and employees with disabilities brings the definition of nursing and the essentials of nursing to the forefront (Arndt, 2004). Does the nursing profession disqualify people with disabilities based on professional requirements? According to Moore (2004), the question of what skills constitute the core essentials of the nursing profession becomes paramount in determining why certain groups of students might be excluded. To exclude nurses with physical impairments labels nursing as a task job rather than the educated, evidenced-based profession nursing has become (Moore, 2004).

The main concern of all nursing educators, nursing employers, and individuals is the question of whether or not a blind person is capable of fulfilling the requirements involved in the nursing profession. More than once, in referring to the researcher's interest in studying nurses who are blind, a person has responded to the researcher, "I wouldn't want to have a blind nurse caring for me!" Ironically, the researcher has informally noted a large percentage of these responses have been from within the blind population. The sighted population has various responses to the idea of blind nurses, ranging from overall reserve and carefully worded questions regarding the blind nurse's capabilities to excitement that with modern adaptations this is now a possibility.

Some articles indicate that there are limitations on the capabilities of blind nurses and attempt to define specifically what roles a blind nurse can have within the nursing

community. One example supporting the idea that blind nurses are incapable of direct patient care came from information provided by a nurse who had lost her vision. The nurse stated in a newspaper article, “I miss hands-on patient contact…I know I cannot do that. I realize my limitations” (Little, 2000). The same article described settings in which nurses have worked, such as phone call quality assurance interviews (Little, 2000). Additionally, another article documented a visually impaired nurse trained in palliative care (”Blind Nurse Graduate Takes a Bow”, 1987). These articles indicate that there are limited opportunities for the blind nurse.

In contrast to the limited opportunities available for blind nurses, students have been admitted to fully participate in classroom and clinical experiences in nursing programs. According to an article, in January 2005, a blind student began her nursing education with support from the National Federation of the Blind (NFB). Initially the college had reservations about the student’s ability to perform in the classroom and clinical experiences. However, the college determined that they would facilitate the student’s education after the NFB described adaptations other blind doctors and nurses are using to be successful in their profession (“Blind woman will pursue her dream of becoming a nurse,” 2005). While educational opportunities were afforded to this blind nursing student, based on the variety of opinions expressed in the literature, it is clear that the capabilities of blind nurses are still highly debated.

Research Questions

This research study is looking at the phenomenological descriptive questions, “What does it mean to be a blind nurse or student nurse?” and “What are the themes and background meanings common to nurses and nursing students with blindness?”

The research explored common themes and background meanings of blind nurses and student nurses. Phenomenology focuses on the personal interpretation of a human response to life experiences and what meaning was gained from the experience. This methodology creates a framework for allowing participants to share their story and experiences as they understand them (Leonard, 1989).

Participants were interviewed in a semi-structured process with general open-ended questions. The interview questions revolved around participants' educational, professional, and personal experiences. Some of the questions included: (a) Describe a specific experience that epitomizes some of the difficulties of working as a nurse/nursing student with a visual impairment. (b) Have there been barriers in accomplishing your professional goals because of your visual impairment? If so, describe an incident where you faced a barrier. Were you able to overcome the barrier? If so, how? (c) If you had blindness or visual impairment during nursing school, please describe a situation during your nursing education that really helped you succeed as a nursing student. (d) If you have worked as a nurse with blindness, please describe an experience when a person, institution, or organization has facilitated your success as a nurse. Follow-up questions were asked as topics emerged and clarification was needed.

Definition of Terms

For clarification of terms used in this paper, "blindness" and "visual impairment" are used interchangeably. Legal blindness is defined by the Center for Disease Control as a best corrected vision of 20/200 or less or a visual field of 20 degrees or less ("Vision Impairment," 2004).

Significance to Nursing

The research of blind nurses is significant to the field of nursing. The research answers questions regarding: nursing ethics, governmental regulations, and the nursing shortage. Each of these areas is further discussed:

Nursing Ethics. Nurses must respond to nursing peers and students in a way that is ethical and based on the moral standards of beneficence, non-malevolence, dignity and fair treatment (Council of Europe, 2006). Research indicates that currently there is huge variation in attitudes towards nursing students and nurses with disabilities. Maheady conducted research on nursing students with disabilities and found they had experienced attitudinal barriers and discrimination (Maheady, 1999; Maheady, 2004). In additional research, nurses and nursing students displayed negative attitudes towards people with disabilities (Shackleford, 2004; Tervo, Palmer, & Redinius, 2004). Another study by Christenson indicates an overall positive attitude of nursing faculty towards nursing students with disabilities. However, the attitude was even more positive if the faculty had previous experience and relationships with people with disabilities (Christensen, 1998). These results indicate there is still a need for more research regarding how negative attitudinal behaviors can be improved. This research provided blind nurses' viewpoints through their experiences and indicated changes that need to be made.

ADA Requirements. Through ADA requirements, the government has created admission and hiring standards for schools of nursing and institutions. In order to comply with the law and avoid accusations of discrimination, it is imperative that nursing faculty and nursing administrators are aware of current policies regarding how to

accommodate students with disabilities. This research provides information on specific accommodations blind participants found useful and suggestions for future improvement in the accommodations.

Nursing Shortage. In an era of nursing shortages in both the workforce and in educational institutions, it is important that nursing look at all resources for individuals interested in pursuing the nursing profession (Maheady, 2006). It is the researcher's hope that sharing the experiences of blind nurses will increase awareness towards these unique professionals and encourage recruitment among the blind population.

CHAPTER TWO

Method of Study

This research is a phenomenological study based on the Heideggerian philosophy and hermeneutics. Each participant is seen as an individual with unique experiences, background, and history. The context in which the person lives and has experienced life is termed "world" (Leonard, 1989). The participants live in reflection; they self interpret their experiences based on their understanding of world. The participants determine significance based on their understanding of world.

The phenomenological method seeks to describe another person's experience (Munhall & Boyd, 1993) through "…a descriptive, reflective, interpretive, and engaging mode of inquiry from which to derive the essence of an experience" (Morse & Richards, 2002, p. 44). The goal of phenomenological research is to understand and see from another individual's perspective—to comprehend their practical and lived experience. The role of the researcher in phenomenological studies is to understand and articulate another person's perspective (Morse & Richards, 2002). According to Heideggerian phenomenology, it is impossible to separate all of the researcher's views from the research process. Therefore, while the researcher focuses on accurately interpreting the participant's viewpoints and responses according to phenomenology, the researcher-participant relationship cannot be sterile and devoid of personal relationship and interaction during the research process. The goal of the researcher in the process of interviewing, gathering, and coding data is to build a relationship between the researcher and the participant in order to accurately assess for meaning and experiences understood by the participant. It is recognized that the researcher has

understandings based on her own life experiences and self interpretation just as the participant does. The researcher cannot remove herself from bias but works to focus on the meanings of the participant rather than her own.

The goals of hermeneutics are practical: "…to understand everyday skills, practices, and experiences…" (Leonard, 1989, p. 51). The researcher then derives meanings from these specific stories and examples as told by the participants. Member checking and an analytic team were used to ensure quality in the interpretive analysis (Lincoln & Guba, 1985; Morrow, 2005; Poggenpoel & Myburgh, 2005). As participants reviewed the themes and stories, they were able to ensure their perspective was accurately represented. Changes and clarifications were made based on participant feedback.

Phenomenology has been said to suitably address the concept of disabilities. Through phenomenology, the participant is viewed as a holistic being rather than categorized by their disability (Patterson & Hughes, 1999). Since no previous research was found regarding nurses or student nurses who are blind, the most appropriate method of delving into this topic was a qualitative study. After researching newspapers and articles and inquiring at blind organizations and nurses with disability groups, it was found that though there are blind nurses and nursing students, the population is limited. Therefore, the researcher determined that a larger scale quantitative study would be impractical. A qualitative phenomenological research study created an opportunity to open up the unknown topic and provide a starting point for further research.

Introduction

This is a qualitative, phenomenological study based on the lived experiences and meaning of being a blind nurse or student nurse. The study included blind nurses or nursing students throughout the United States with a participant size of four. The research was done through semi-structured open ended interviews via telephone and email. Member checking, as well the use of an interpretive team during analysis, improved rigor. Additionally, findings were compared with those in other disability studies.

Type of Design

This study is a qualitative descriptive design using Heideggerian philosophy. Data were collected through open-ended interview questions with additional probes as needed to gain additional information. The researcher sought out concrete incidents and experiences (Chapin & Wittman, 2005).

Population and Description of Participants

The sample of this study was comprised of four blind nurses or nursing students. Participants self-reported legal blindness. Because of the limited number in the population, participants were from a wide geographic distribution. Nurses and students were recruited through purposive and snowball sampling. Invitations to participate in the study were sent out through large blind organizations such as the National Federation of the Blind and the American Council of the Blind via their respective websites. In addition, an invitation was sent through “Nurses with Disabilities” periodic newsletter. Visually impaired nurses and nursing students gave the researcher contact information of other eligible participants.

Rigor

Rigor was insured by accurate transcription and member checking of the information. This format was used to ensure that coding was appropriate to the meanings the participant indicated and themes match the information gained in the research interviews. A research analytic team reviewed the data to ensure the researcher was not relying on her single perspective. The researcher compared findings to other disability studies in order to enrich interpretations. The researcher kept an audit trail of all researcher's decisions, collection times, and decisions made in the research process.

Lincoln and Guba addressed the issue of rigor through four evaluative measures which were used in this study. These evaluative measures include credibility, applicability, consistency, and neutrality (Lincoln, Y. & Guba, E., 1985; Morse & Field, 1995; Munhall & Boyd, 1993). Sandelowski further described evaluative measures. Credibility is oriented around accurately telling the participant's story and experience in the way they have described. It is the participant's truth that the researcher is describing. Applicability refers to how well the information can be used in other situations. Consistency is determined through whether or not similar concepts and themes emerge. Because each individual is unique, it is expected participants will have differences in their experiences and understanding of those experiences. However, themes drawn from the study should be clearly noted in the data and the reader should be able to discern the themes to validate the findings. Authenticity is achieved through keeping the researcher's own self-interpretation from that of the subjects and accurately describing their experiences rather than the researcher's (Leonard, 1989).

Data Collection Procedure

Because none of the participants were within a two hour driving distance from the researcher, the option of telephone, email or instant messaging was given to the participants. As with any group of individuals, communication styles vary and the goal of the researcher was to use a format that would create the greatest comfort and willingness to communicate and share information based on individual preference. Thus, data were collected based on participant preference. Two participants chose phone interviews, and two participants chose email interviews.

There has been debate regarding the importance of non-verbal communication in getting quality data from participants. Some have argued that quality interviewing cannot be accomplished without face-to-face interviews. Others argue it is possible to get good data if the interviewer's online technique builds participant rapport (Beck, 2005).

Internet modes of communication also add flexibility for participants and follow-up opportunities for the researcher. This flexibility in method of data collection was found beneficial in a phenomenological study of disabled students (Chappin & Whitten, 2005). Some participants respond more openly to questions via web based conversation than in a face-to-face setting. In addition, follow up questions can be used throughout the process to prod participants for more information (Curasi, 2001).

In a study, Beck (2005) evaluated the responses of participants after they took part in an online study. She found that the participant's experiences with the online qualitative study were markedly similar to the expected experiences of women involved in face-to-face qualitative studies. Beck offers suggestions to carefully word emails to

convey “caring and respect” to allow for a positive interacting relationship to build between researcher and participant (Beck, 2005, p. 421).

Two separate one hour phone interviews were planned for two participants. The researcher verified information and confirmed themes with the participants through follow up emails as needed. Email interviews were scheduled for the remaining two participants. Participants were encouraged to spend no more than one hour answering the interview questions at a time convenient for the participant. The interviews were continued until data saturation was accomplished.

Data Analysis

Data analysis was done by coding the information based on topics and ideas that emerged. The researcher copied responses and phrases, as written by the participant, into a document under codes the researcher determined based on the data content. After coding, the researcher assessed for themes indicated by the participants’ responses. The researcher went back to participants with themes to assess credibility in the interpretation.

Human Subjects Considerations

Informed consent was given and signed by each participant before taking part in the study. The informed consent was given to the participant in the media of his/her choice and all participants opted for an email copy of the document. (See Appendix B for the informed consent document.) The informed consent was seen as a process (Larossa et all, 1981). The participant could, at any time, withdraw from the study, revoke information, or decline to answer questions. Participants were made aware that

any other method than face-to-face interview has potential risk of outside tapping into internet or phone call conversations.

Because of the small population of blind nurses and nursing students, it was important to make sure participants understood that the researcher is not able to fully assure participants' confidentiality. In keeping with the convention of this method and because of the inability to guarantee confidentiality, the researcher gave participants the option of "owning their story" by using actual names as desired by the participant. Two participants chose this option. For participants preferring to remain as anonymous as possible, names and places were undisclosed in the research paper. Participants were given the opportunity to decline participation in the research or withdraw any information they felt might jeopardize their confidentiality if they were uncomfortable with the issue of confidentiality (Streubert & Carpenter, 1999).

Blindness is a disability and therefore categorizes the population being studied as a vulnerable population. Care was taken, by the researcher, to create an environment free from discrimination or stereotyping. The participants were made aware that he/she could, at any time, pause or stop the interview, or decline to answer specific questions. The researcher did not prod if the participant appeared uncomfortable or hesitant in giving information. None of the participants became upset or caused the researcher to feel that the participant needed more extensive follow-up for issues that emerged in the interview process.

CHAPTER THREE

Nurses with Disabilities: a phenomenological study of nurses who are blind

The Journal of Nursing Education

Abstract

The purpose of this study was to explore the experiences and role of blind nurses and nursing students. The Heideggerian phenomenological method was used to research the lived experiences of four blind nurses recruited through purposive sampling. In addition to the study's phenomenological framework, the social model of disability theory guided the research. Four participants were interviewed in individual interviews via telephone and email. Each participant described his/her experiences as a blind nurse and/or nursing student. The following themes emerged during the interview discussions: barriers to nurses with visual impairments, strategies to overcome barriers, role modeling as a minority nurse, safety concerns with visual impairment, and accommodations under the American with Disabilities Act (ADA). Conclusions include recommendations for culturally competent education and suggestions for workplace support.

Introduction & Condensed Review of Literature

Articles about nursing students with disabilities are springing up in nursing literature with a call for nursing faculty to accept and accommodate these students' needs (Arndt, 2004; Bohne, 2004; Carroll, 2004; Evans, 2005; Maheady, 2004; Persaud & Leedom, 2002; Selekman, 2002; Wright & Eathorne, 2002). The literature also indicates that nursing students with disabilities encounter attitudinal barriers that are more debilitating than their physical barriers (Maheady, 1999; Marks, 2007). One

research study found that negative faculty attitudes can be decreased through educational implementations (Sowers & Smith, 2005). No research was found that studied the experiences of blind nurses or nursing students.

Research Design

This phenomenological study is a qualitative descriptive design using Heidiggarian philosophy to unveil the lived experiences of nurses and nursing students who are blind. Data were collected through open-ended interview questions with additional probes to answer "What does it mean to be a blind nurse/nursing student?" and "What are the themes and background meanings common to nurses/nursing students with blindness?" Quotations are used liberally in reporting the findings in order to fully express the meanings and experiences that the participants described. The social model of disability was utilized as a framework for viewing disability from a holistic, cultural perspective.

Results

A total of four participants, two Registered Nurses, and two nursing students were included in this study. Participant ages ranged from 36 to 48 years. Three participants were female and one participant was a male.

Participants were located in four states and were given the option of telephone, email, or online chat interviews. Two participants opted for a phone interview and two opted for completing their interview by asynchronous email.

All participants were self reported legally blind, and all participants had some useable vision and were able to read print with low vision aids. The eye conditions identified by participants were Usher's Syndrome, retinopathy of prematurity,

Stargardts, and macular degeneration. Three of the four participants went through nursing school with a visual disability.

Because of the limited population of blind nurses and nursing students, the informed consent, approved by the institutional review board (IRB), described the inability of the researcher to guarantee anonymity. Participants were given the option of owning their story. Two participants, Nicole and Pamela, chose to have their identity used in the final research while two participants opted to have their names and details obscured.

Barriers. The two barriers described most frequently were barriers due to faculty and staff nurse attitudes and technology. Nicole indicated her surprise of the nursing faculty's response to having a blind student when she stated:

> *I had no idea what I was up against. I thought in my little fairy tale world that I was going to go to school and everyone was going to be, "Oh, wow, great! You are visually impaired. What can we do to help you out." Cause they're nurses, right?*

Nicole encountered problems with nursing faculty insisting that requirements be "fair" to the other students while denying Nicole accommodations such as syringe magnifiers and digital thermometers. She was told she needed to be able to read the glass thermometers like the other students in order to promote fairness.

Kim also recalled experiences in nursing school when faculty insisted that Kim perform equal to the sighted counterparts in the traditional nursing school setting without accommodations.

I had done more IM, IV, and SQ sticks than any nursing student has in their life! I don't think it was…(the) faculty's goal to create a prolific sticker. I think it was their intention to prove I couldn't do it… Their thing was, "We are going to treat you like a regular student, and you need to prove you could perform in this system."

Kim stated that non-nursing instructors were helpful by giving copies of their overheads a month ahead of time. The nursing faculty, on the other hand, told Kim to get class notes they wrote on the board from another classmate.

When Nicole requested to use a sphygmometer that was easy for her to read, she was told by her clinical instructors that taking the cuff from room to room was a patient safety concern (even though staff members commonly did this). Nicole was able to have her equipment approved directly through the hospital's safety department.

Nicole ran into additional attitudinal barriers with hospital staff as well. A staff nurse observed Nicole reading a patient her discharge papers. In order to see the information, Nicole held the papers up close to her face and used her glasses and monocular. The nurse approached Nicole's instructor lamenting over the "poor student having trouble reading." Shortly afterwards, the hospital manager reported to the school that the patient had complained about Nicole's inability to see. However, Nicole recalled this particular patient hugging her and telling her what a wonderful nurse she would make. Nicole stated that she knew the patient was not the person with concerns but rather the concerns belonged to the uncomfortable staff nurse.

Nicole described another situation where she struggled against instructor attitudes.

Two of my instructors asked me to meet them in their office… They handed me a piece of paper and asked me to read the name highlighted. I did not have my

reading glasses with me…So I said the name was either Michelle or Michael. The font was very, very small, maybe 8 to 10 font, plus it was highlighted with a blue marker making it more difficult to read. The instructors said that was the same size font on patient armbands. I told them that every armband I had ever read was much larger font than that, but my instructors disagreed... I didn't know what to say because at the time I didn't have any idea what my rights were. But I did know I was being discriminated against.

After several such frustrating experiences, Nicole concluded she was being set up for failure and withdrew from the program.

Nicole began researching her rights as a student with a disability. Nicole was offered admission into other nursing schools because of the difficulty she had experienced at the previous college. However, Nicole was determined to go back and finish where she started. She longed to bring about a change in the program's treatment of students with disabilities.

Kim went to seek out an education funding source and ran into an attitudinal barrier within the commission for the blind.

I knew I could access the commission for the blind for help to get me through school…For the next three or four months every time I'd go I'd hear the same thing. "We have this wonderful program. We are going to teach you how to run a restaurant…" I kept saying to them over and over…I don't want to run a restaurant. I want to be a nurse!

Kim appealed to the commission and finally received the financial support needed to pursue a nursing career.

When Kim conversed with the chairwoman of the nursing department about becoming a nurse, Kim received conflicting messages regarding Kim's nursing goals.

> *I was talking with her about stuff, and she goes, "There's no reason you can't be a nurse…You'll never be able to work in an emergency room, or in critical care, or in an ambulance, or where you need to watch monitors… But you'll be able to do med-surg or nursing leadership or education." …It just got me madder than heck underneath the collar. So the first thing I wanted to do was work critical care. I've worked dialysis... the emergency room as a float nurse….It was like, I'm going to empower you, but I'm going to tell you you can't do it.*

Kim refused to be limited by what the blind commission or nursing department felt were reasonable goals and determinedly went on to defy the boundaries others had placed for blind nurses.

In addition to the frequently mentioned barrier of instructor and nurse attitudes, Kim described a large concern in regards to the technology system health care facilities use for computer entry, charting, and print outs. For instance, the medication administration records are printed in ten point font and the ink is often faded. This makes it difficult for Kim to see the medication directions, and the process of using the magnifier to distinguish each letter is grueling. Likewise, Nicole stated that the lap tops the nurses take into the patient's room have ten point font, which was too small for her to see. Kim identified that while technology has increased accessibility options, it is up to the purchaser of the technology to purchase equipment that is adaptable to the needs of the visually impaired employee.

Strategies

Participants worked to identify strategies to overcome barriers they encountered. The strategies identified are founded in self-advocacy. One strategy used by participants was to determine whether or not to disclose their visual impairment to the employer or nursing school and, if so, at what point this should be done. "To tell or not to tell" became a strategy to achieve admission to a school or gain employment. Kim explained this decision about disclosure:

> *When I apply for a job I don't put down that I am visually impaired. I've found over the years if I put that down there I don't get the interview. And I think I am fairly well qualified. I mean, I hold a bachelor's degree in nursing and another bachelor's degree in a different field and a master's in [another discipline]. But if I put down on the application…that I am legally blind, I can tell you without a fault that I don't get an interview.*

After an interview, when disclosing the visual impairment, Kim stated the interviewer is usually very surprised. However, they are then able to discuss any implications the visual impairment may have.

Nicole also chose to withhold information about her visual impairment when applying for nursing school. With the second highest entrance score, she was quickly admitted into the program. However, when she disclosed her disability at orientation, she received a concerned response from faculty. "…they all just looked at me… they had so much fear in their faces. They were like, you want to be a nurse, and you can't see?"

Afterwards Nicole decided to take on a new strategy of meeting with instructors or staff at clinical sites prior to working on site. She explained:

> *I try to be like, "I have a vision impairment. It's OK, don't be scared! This is your opportunity to ask questions. I am letting you know so that I can clarify any misconceptions and alleviate any concerns you have. I'm here. I'm approachable. You're not going to offend me by asking questions." If I display confidence and approachability, (nurses) tend to become…comfortable with the idea of a visually impaired nurse more quickly.*

Nicole found openness was a helpful way to alleviate staff concerns.

Chris also debated over when and how to disclose the visual impairment. Chris stated:

> *I was reluctant to register myself as a disabled student with the school because I thought that if I made a mistake, they would find ways to kick me out of the program. Even though it is pointed out that the school does not discriminate those with disabilities, I didn't want to take a chance.*

In contrast to the other two participants, Chris found positive support from faculty. Prior to disclosure, nurses were impatient and frustrated with Chris for being slow or not seeing things. However, after the visual impairment was disclosed, faculty bent over backwards to ensure Chris's success in nursing school.

Unlike Chris, other participants experienced difficulties after disclosing their blindness to instructors. One participant described his experience:

> *(The nursing school) said that there was absolutely no way…a blind nurse could be employed, and they refused my application. So I went to the state board of nursing, and the state board of nursing said, "No, under ADA you have to let him*

(enter the program)." …Four and half years later when I went to graduate…the board of nursing then came back to me and said, "We can't license you"…

The nursing board, in order to validate their refusal to license a blind nurse, used documentation from an ophthalmologist which stated that no one with vision less than 20/40 should be employed in health care. After further discussion between the school, the board of nursing, and the participant, the license was finally granted.

Another participant also struggled to gain faculty support. Nicole went to a vocational rehabilitation counselor for help with accommodations. After conferring with the nursing department, Nicole's counselor stated that faculty had determined she was a safety hazard. Because of this, Nicole lost her educational fund for nursing. Despite this painful set back, Nicole became her own advocate and began to learn her rights under the ADA. A year later, as a result of Nicole's determination, a lawyer from the state disability advocacy program met with the school, and Nicole was readmitted to the program. After having successfully passed one semester, the vocational rehabilitation funding was reinstated.

Just as self advocacy was an important technique for participants in their nursing education, this skill became equally important later on in the workplace. Kim explained that self advocacy is the only way to ensure workplace accommodations. "I have always had to be the person that had to raise my hand and push the issues… when I push long enough or push hard enough or say the magical words (ADA) then they are more than willing…" More specifically, Kim described responses that were necessary when an employer argued about the cost of an accommodation." Kim has determined to give specific facts regarding the budget, the cost of the accommodation, and the cost

of losing a nurse if Kim can no longer do the job. This strategy has worked well for Kim, and there has never been an instance where legal representation has been needed.

Self advocacy also led participants towards finding supportive organizations. These organizations included disability departments, the state board of nursing, commissions for the blind, national blind organizations, and nurses with disabilities organizations. Just as other types of self-advocacy were essential to the participants' success, each participant found support, strength, and resources in organizations which helped them successfully continue their pursuit of a nursing career.

Role Model. The participants became forerunners for students with disabilities. Later in her education, Nicole described watching a disabled student enter the program. Nicole stated that the instructors had a much different attitude with this student. She was encouraged that her struggle had paved the way for future students.

Pamela had an opportunity to provide peer support to a struggling nursing student. Pamela was able to use her experience to give the student ideas for accommodations in the clinical setting and was able to encourage the student to successfully continue her education. Pamela expressed a great sense of accomplishment and good coming out of her vision loss.

Participants' described the expertise and proficiency they had developed in their role as a nurse. For instance, if staff is having difficulty inserting an IV, Kim is called because of Kim's expertise with IV starts. A nursing instructor told Nicole that out of all the nurses she knew she would pick Nicole to care for her family because of Nicole's conscientious nursing care. These situations highlight achievements made by the participants and their role modeling of exceptional nursing care.

Safety. Safety is one of the biggest concerns in literature when debating the issue of nurses with disabilities. Safety was brought up several times in the interviews, indicating it is also a cause of concern for blind nurses.

Nicole encountered a situation in which her blindness could have potentially caused an error. Nicole explained that, in this instance, she had an order to administer insulin, and she thought the medication order said 10 units when it said 18. Though she caught the error, Nicole was terrified that she could have made a mistake due to the small font on the computer. At her request for accommodations, the hospital now provides a computer that has screen magnification. The computer is mobile, and Nicole is able to take it into the patient rooms, thus ensuring patient safety.

Pamela exemplified her immense concern with safety and her willingness to sacrifice her career in dialysis when she felt her patient was in jeopardy. She described her experience:

> *I thought I had all the lines clamped but couldn't visualize them. The machine started to alarm with "Air in the Line" alarm, which automatically shuts off the machine, thankfully. I had let a 500ml bag of saline run completely dry, but my eyes couldn't see that…This was my last day in dialysis as I was so afraid that I would do more harm than good.*

This situation demonstrated that Pamela was able to put patient safety above her career. Pamela stated she has since discovered that there are accommodations and strategies that she could use which would aid her in returning to her work in dialysis. At the time the situation occurred, however, she recognized her limitations and her highest priority was providing safe patient care. Nurses in this study indicated that they

understood their limitations, knew what they felt safe doing and had ideas for adaptations and improvements to system issues. The participants indicated that they were not going to step outside of what they felt were their limits in providing good nursing care.

Accommodations. The ADA was core to the success of the participants in nursing school and in gaining and retaining employment. But, while the ADA ensures that the school must make accommodations, it does not specify those accommodations. Nicole described the complexity of figuring out clinical accommodations in a new setting by stating:

> *…the skills that you've used all your life to improvise and adapt are gone because you are in a completely unfamiliar environment. They are immobile... All eyes are on you because you are a nursing student. But when they find out you are a nursing student with a visual impairment than all eyes, plus the magnifier, are on you! And it's the anxiety…that I think is really more debilitating than my vision.*

Nicole described an obvious hurdle for students in an unfamiliar setting. The accommodations and strategies must be discovered often in stressful circumstances. Instructors and managers are likely having their first encounter with a visually impaired nurse/nursing student. Growth and learning will have to occur as instructors and students strategize together to discover accommodations that will work in the clinical setting.

Kim described accommodations that were found useful. The most memorable accommodation was used when Kim was working at a government facility. Kim's

employer cut a four foot hole in the edge of a wall to install a computer specifically for Kim's use. Kim also had accommodations in the NCLEX. The exam was taken privately with magnification equipment over a three day period to prevent eye strain.

Another type of accommodation was a culturally sensitive attitude toward students with visual loss. Positive attitudes from nurse faculty and managers created an atmosphere of acceptance and accommodation. Nicole was welcomed by a pediatric nurse mentor. This nurse mentor affirmed Nicole's value as a nurse with a visual impairment and encouraged Nicole to show the young patients her adaptive equipment. The mentor told Nicole that she is a role model for pediatric patients and a living example that they can also grow up to accomplish their dreams. Kim also described a current nurse manager's helpful attitude and how she provided large print memos and emails in Kim's font preference. Nicole emphasized that having a positive encouraging attitude was the number one way that nurses and faculty could help their visually impaired students.

Among the previously listed accommodations, the participants listed some practical accommodations that they discovered, including: syringe magnification devices, computer screen magnification software, and magnification aids. Participants also mentioned spending time familiarizing themselves with new clinical settings, exploring accessibility options on equipment, and collaborating with experienced nurses to discover possible adaptations to nursing care.

Discussion and Implications

In the midst of negative attitudes and faulty perceptions, participants in this study displayed strong self-advocacy skills by requesting necessary accommodations. The

barrier of faculty attitudes towards students with disabilities was documented in the literature review (Maheady, 1999; Marks, 2007). The participants' determination to overcome attitudinal obstacles is echoed in Maheady's study of nurses with disabilities (Maheady, 1999).

This study gave examples of visually impaired nurses and nursing students who are role models in their profession and are changing attitudes towards nurses with disabilities. Blind nurses are diversifying the nursing workforce and creating an opportunity to challenge those within nursing to focus on abilities and nurses as knowledge workers rather than categorizing or limiting people by their disability.

Blind nurses are advocating for safety measures to ensure their ability to perform quality patient care. Nursing literature by Arndt (2004) states that it is discriminatory to believe a nurse with a disability would not be guided by the same ethical principals as other nurses. Visually impaired nurses' are aware of potential limitations and desire to protect patients.

Accommodations should be viewed as providing an equal playing field rather than special privileges. Speaking words of encouragement, providing screen magnification, and hosting staff question and answer times offer practical ideas for accommodating a visually impaired. A nurse educator wrote, "Fairness is achieved not through treating everyone the same, but rather giving each person what he/she needs" (Arndt, 2004).

Findings from this study can assist faculty in awareness of their own attitudes towards blind students. Education on the rights and abilities of the visually impaired is

important to the prevention of unnecessary law suits, negative publicity, and the success of blind nurses.

Recommendations for Future Research

A study comparing the experiences of completely blind nurses with the participants in this research would be beneficial. Interviews of faculty, managers, and patient experiences working with a blind nursing student or nurse would also provide rich insight into the education and employment of blind nurses. Further study of specific disability types and ways to improve attitudes towards disabled students is imperative.

Limitations

Multiple interview formats resulted in some limitations for this study. The interviews done over the phone proved the most in depth and data laden because of the ability to quickly ask questions or discuss topics that emerged.

Another limitation of the study was the lack of completely blind participants. However, as this research mirrored themes of a previous study on nursing students with disabilities (Maheady, 1999), and it is likely themes would have remained consistent.

Conclusion

Blind nurses and nursing students who have succeeded educationally and professionally had determination to overcome barriers through self advocacy. These nurses helped pave the way for future blind nurses. In addition to understanding the legal rights of disabled nurses, nursing faculty and managers should be aware of any attitudes that may provide barriers to blind nurses' success. As these attitudes change and accommodations are implemented, blind nurses are empowered to bring their valuable contributions to the nursing profession.

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Appendix A

Informed Consent

WASHINGTON STATE UNIVERSITY
CONSENT FORM

Nurses with Disabilities: a phenomenological study of nurses who are blind

Researcher: Sarah Buttrell, RN, BSN

Graduate Student, Washington State University Vancouver

223 Desota Rd, Woodland, WA 98674

(Home) 360-225-4498, (Cell) 360-907-2728, (Work) 360.696-6321 x 123

Researchers' statement

I am asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When I have answered all your questions, you can decide if you want to be in the study or not. This process is called 'informed consent.' I will give you a copy of this form for your records. Always remember that informed consent is a process and you can choose to stop your involvement in the research at any time.

PURPOSE AND BENEFITS

The purpose of this research is to explore an area of nursing that is not yet researched. There has been an increase in nursing literature about nurses with disabilities but none that have focused on nurses or nursing students who are blind. This study will interview approximately four nurses and nursing students with blindness to record their life experiences as a blind nurse and/or blind nursing student. The goal of this study is to increase awareness towards the experiences of nurses with disabilities, specifically those who are blind, by educating nurse faculty and the larger nursing community with stories and examples of your experiences. If barriers are identified in the research, recommendations to overcoming these barriers will also be analyzed.

PROCEDURES

The study will be done in individual interviews. To maximize your ease at completing the interviews at a time and in a format most compatible for you, it will be your decision whether to do the interviews via telephone, email, or instant messaging. For

participants within two hours of the researcher, the participant will also have the option of a face to face interview. Please remember the only true secure method of communication is face-to-face communication as information can be tapped into through cell phones or internet communication.

Because of the various forms of communication methods that are possible, the length of time may vary depending which method is chosen. An in-person or phone interview will take approximately one hour of your time. There will be approximately five questions you will be asked regarding your experiences as a nurse and nursing student. You will need to be specific in examples and experiences you recall. I will ask you follow up questions to make sure I understand you correctly and to help you add more details to your responses. The interview will be recorded either on tape for phone or face-to-face interview or through electronic documents if the interview is done via email or instant messaging.

Once the initial interview is complete, I will record the data you gave me in the interview. I will then contact you to make sure that I have correctly understood the information. You will be able to correct any misunderstandings or remove data at any time during the research process.

The questions you are asked will be directed towards your personal experiences. The researcher foresees the most concerning questions for you to answer would be if your experiences with nursing faculty, coworkers, or supervisors that were negative or harmful to you. In order to prevent any harm to yourself, please consider carefully whether you would be willing and able to give information regarding your personal experiences before agreeing to participate. If you choose to participate, please remember that at any time you can withdraw from the study or refuse to answer a question with no repercussion.

The only personal medical information needed for this study is verification of your blindness. This can be given through a doctor's verification or government paperwork indicating your legal status as a person who is blind.

RISKS, STRESS, OR DISCOMFORT

Depending on your experiences, retelling life experiences may cause emotional stress or discomfort. You have the right to refuse to answer any question for any reason. You may choose to end the interview at any time. If the interview is creating significant distress as deemed by you or me, the interview will be stopped and you will be released from further participation in the research. I may recommend follow up counseling; however, all counseling or medical costs associated with the interview will be your responsibility.

OTHER INFORMATION

Because of the small number of nurses and nursing students who are blind, there is no way to ensure that all the information will stay confidential despite detailed efforts to confidentiality. Because of the possibility that individuals or organizations may be able

to identify your stories and examples, please consider carefully your willingness to participate. For example, a nursing instructor or supervisor reading this article may be able to recognize your identity even if your name and any identifiers were changed. Please consider any possible ramifications if your experiences highlight topics that would be negative towards their reputation.. If topics of abuse or harassment are shared, the information may become public information and subject to supeona. You will be given the option to own your story by allowing me to include identifiers such as your name and affiliations in the final research document. However, if you would prefer to remain as anonymous as possible, your name and identifiers will be changed to decrease the likelihood that you will be identifiable in the research. You will also be given the right to retract any information that you later feel could jeopardize your confidentiality, excluding information subject to supeona.

Once you have participated in the initial interview, I will mail you a check for $50.00 as a stipend for your time, travel, and other small costs that may be associated with participating in this study such as cell phone minutes and Internet access. You will receive the payment regardless of whether or not you are able to complete the entire interview process.

MEDICAL RECORDS ACCESS

I will not need access to any of your medical records.

_____

Printed name of researcher Signature of researcher
Date

Subject's statement

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have general questions about the research, I can ask one of the researchers listed above. If I have questions regarding my rights as a participant, I can call the WSU Institutional Review Board at (509)335-9661. This project has been reviewed and approved for human participation by the WSU IRB. I will receive a copy of this consent form.

_____

Printed name of subject Signature of subject
Date

Appendix B

IRB approval form

WASHINGTON STATE UNIVERSITY HUMAN SUBJECTS FORM
April 2005 Version

To receive approval from the WSU Institutional Review Board (IRB) for the use of human subjects, submit the following packet of materials to your department for initial review and signatures. Your department will forward the packet to the IRB for final review and approval. When your packet has been received by the IRB it will be checked for completeness. If not complete, it will be returned with a request for additional materials necessary for the review.
To determine the level of review needed for your protocol turn to Section 2, Page 6.

PACKET CHECKLIST

UEVERY PACKET MUST INCLUDE THE FOLLOWING MATERIALSU.

1. Completed and Signed WSU Human Subjects Forms ___
2. Documentation of Consent Procedures (one or more of the following):
   a. Consent Form, ___
   b. Verbal Consent Script,
   c. Cover letter.
   d. Wavier Request
3. Any survey instruments or questionnaires to be used. ___
4. A list of interview questions or topics, in as much detail as possible.
5. If you are accessing protected health information (PHI), complete and attach a completed ___
   HIPAA Authorization Form & HIPAA Appendix A
6 Any advertisement or recruiting materials ___
7. **Exempt protocols**: Signed original ___
   Expedited Protocols: Signed original and two copies of items 1-5.
   Full Board Protocols: Signed original and 16 copies of items 1-5.
8. **Original** must be Usingle-sidedU and Unot stapledU. **Copies** may be UstapledU and Udouble-sidedU.

AVOID THE TOP 5 MISTAKES PEOPLE MAKE WHEN SUBMITTING AN APPLICATION!

1. Stating that the data is anonymous when it is actually confidential (See Section 5, Definitions).
2. Not giving enough information as to who will have access to the data.
3. Stating there are no risks to a project. Even though the risks may be low, they need to be listed on the form.
4. The signature page does not have all the required signatures.
5. Consent forms and survey or interview instruments are not attached for review.

REVIEW TIMETABLE

Exempt reviews are reviewed as the packets are received and will take no more than 10 working days for approval once they have arrived at OGRD.
Expedited reviews are reviewed as the packets are received and will take about 12 working days for approval once they have arrived at OGRD.
Full Board reviews will be reviewed at the next monthly meeting of the IRB, Uif and only ifU the packets are received at OGRD at least 10 working days prior to the meeting date.

ELECTRONIC VERSIONS OF THIS FORM

Use contact number below to request copy.

WORLD WIDE WEB SITE at www**.research-compliance.wsu.edu** under **IRB**.

HOW TO CONTACT THE IRB

Phone:	(509) 335-9661, Research Compliance Office
Campus Mail:	campus zip 3140
Fax:	(509) 335-1676
Email:	irb@wsu.edu
Mail:	WSU IRB, PO Box 643140, Pullman, WA, 99164-3140

SECTION 1

PLEASE TYPE. If you use an electronic version of this form, use a different font for your responses.
DO NOT leave a question blank. If a question does not apply to your protocol write "n/a."

Principal Investigator(s) (PI):__***Sarah M. Buttrell***_____

Department:***Nursing***_____
Campus:***Vancouver***_____ Campus Zip:***98686***_____

Campus Building & Room #:_____***N/A***_____

Status: Faculty____Adjunct Faculty____Staff_____Graduate Student
X___Undergraduate_____

Contact Phone Number:_***360-907-2728***_____ Contact Email Address:___***sarahbuttrell@hotmail.com***

Mail Correspondence To: ***223 Desota Rd Woodland, Wa 98674***

Project Title: ***Nurses with disabilities: a phenomenological study of nurses who are blind***

TYPE OF REVIEW: EXEMPT___ EXPEDITED___ FULL BOARD_***X***__

Estimated project start date: ***11/06*** Estimated data collection completion date: ***2/06***
Is there, or will there be extramural funding that directly supports this research? YES ____ NO__***X***__
If yes, funding agency (s):_____ PI on grant:_____
OGRD# _____

ABSTRACT: Describe the purpose, research design and procedures. Clearly specify **what the subjects will do**.

The purpose of this study is to explore the experiences and role of blind nurses in the nursing profession, in order to better understand the role of the blind nurse. The phenomenological method was used to research the lived experiences of four blind nurses, recruited through purposive and snowball sampling. In addition to the phenomenological method, the theoretical guide for this study was the social model of disability theory. Four participants will be interviewed in individual one-on-one interviews in the format of their choice to maximize flexibility and opportunity. These methods include face-to-face interview, telephone interview, email interview, and/or instant messaging interview. The participants will be asked to give specific examples of their experiences as a blind nurse in nursing education and/or the nursing workplace. There will be one initial interview that will be 1-3 hours long with scheduled

hourly breaks. Follow up interviews will be scheduled as needed to build richness to the data and to allow for member checking.

I. DATA COLLECTION

A. Check the method(s) to be used **(underline all items in the columns on the right that apply)**:

___ Survey: Administered by: investigator subject mail phone in person internet/email

_**X**_ Interview: one-on-one focus group oral history other

If you are using a survey or doing interviews, submit a copy of the survey items/ interview questions

Interview Questions:

- ***Please tell about an incident that captures the most positive aspect of your role as a nurse.***
- ***Can you think of an episode that epitomizes some of the difficulties working as a nurse?***
- ***Have there been barriers in accomplishing your professional goals; if so, describe an incident where you faced barriers. Were you able to overcome the barrier? If so, how?***
- ***Please talk about a situation during nursing education that really helped you succeed as a nursing student.***
- ***Please describe an incident where a nurse manager or institution facilitated your success as a nurse.***

__ Observation of Public Behavior: in classroom at public meetings other

___ Examination of Archived Data or Records: academic medical legal other (briefly describe)

_____

___ Taste/Sensory Evaluation: food tasting olfactory

___ Examination of Pathological or Diagnostic Tissue Specimens

___ Therapeutic: biomedical psychological physical therapy

___ Experimental: biomedical psychological other

___ Other: Briefly Describe _____

_____

B. Data: Anonymous ___ Confidential _***X***_ Intentionally identified_***X***_ (**Please See Definitions, Section 5**).

C. What form of consent will be obtained? (**Please see Section 6 for sample consent and assent templates**)

a. Implied ___ (Please attach cover letter or describe terms.)
b. Verbal ___ (Please attach consent script.)
c. Written _***X***_ (Please attach consent form.)
d. Seeking Waiver of Consent ___ (Contact the IRB for further information.)
e. Consent Not Applicable ___ (On a separate page explain why not.)

D. If anonymous or confidential, describe how anonymity or confidentiality will be maintained (e.g., coded to a master list and separated from data, locked cabinet, office, restricted computer, etc..). List all sites where data might be stored.

Data will be kept confidential through coding data to remove identifiers from participants. All pertinent data will be kept in a personal secure computer. Any hard copies will be kept in a locked cabinet in the researcher's home office.

E. Who will have access to the data? Please be specific.

The researcher will have access to the data as well as those used for peer review and checking. This will include the research committee and the analytic team working to analyze the data. Identifiers will be removed prior to data analysis.

The researcher and the research analytic team.

F. Will video tapes ___ audio tapes _***X***_ photographs ___ be taken? YES _***X***__ NO____
If yes, where will tapes or photographs be stored?

The audio tapes will be stores in a locked cabinet with any other non-electronic data collected.

G. When will all research materials be destroyed?

After the research is published, all research materials will be destroyed.

II. DESCRIPTION OF THE POPULATION (See Definitions, Section 5, Page 9)

1. Approximate number: __***4***_____ Age Range: __***Over 18***_
How will subjects be selected or recruited and how will subjects be approached (or contacted)?

Subjects will be selected based on eligibility: legally blind, a nursing student or working as a nurse within the last five years, female gender.

2. Will subjects be compensated* (include extra credit)? YES _***X***__ NO____
If yes, how much, when and how. Must they complete the project to be paid?

All participants will receive a $50 stipend after participation in the first interview. If the participant chooses to end participation at any time during or after the first interview, the participant will still receive the stipend.

*NOTE: If students will be receiving extra credit for participation, they must be able to complete an alternative assignment for extra credit should they choose not to participate. This assignment must be comparable, with respect to time and effort, as participation in the research.

3. Are any subjects under 18 years of age?
YES_***X***__ NO___

4. Are any subjects not legally competent to give consent? YES ____
If yes, how will consent be obtained? From whom? Are there procedures for gaining assent?
(Please attach assent form.)

5. Will any ethnic group or gender be excluded from the study pool? YES ___ NO__***X***__
If yes, please justify the exclusion.

6. Is this study likely to involve any subjects who are not fluent in English? YES ____
If yes, please submit both the English and translated versions of consent forms and surveys, if applicable.

7. Does this study involve subjects located outside of the United States? YES ____
If yes, on an attached page please explain exactly "who the subjects are," and the identities (if possible) and
responsibilities of any additional investigators.

8. Does this study involve the use or creation of protected health information? YES __***X***__
(See Section 5 for a definition of protected health information.) If yes, complete and submit HIPAA Appendix A, the HIPAA Authorization Form along with the completed human subjects
application.

III. DECEPTION (See Definitions, Section 5, Page 9)

If any deception is required for the validity of this activity, explain why this is necessary. Please include a description of when and how subjects will be debriefed regarding the deception, and **attach a debriefing script**.

N/A

IV. RISKS AND BENEFITS (See Definitions, Section 5, Page 8)

A. Describe any potential risks to the subjects, and describe how you will minimize these risks. These include stress, discomfort, social risks (e.g., embarrassment), legal risks, invasion of privacy, and side effects.

Risks to the participant: Confidentiality will not be guaranteed based on the small population of nurses with blindness. This is clearly outlined in the informed consent and participants are given the opportunity to either own their story by keeping identifiers in the finished research product, or to remain as anonymous as possible through changing identifiers. Participants can retract or refuse to give any information that may cause them to be recognized. However, the researcher recognizes this will not guarantee anonymity.

If the participant had negative experiences related to nursing education and/or workplace situations, the retelling of these experiences could cause stress and emotional discomfort to the participant. The informed consent details this risk. In addition, the participant will be observed by the researcher for any verbal and

non-verbal indicators, should the interview be in person or telephone (including decreased responses, long pausing, flushed face, arms folded, stammering etc.), of reluctance of discomfort in participating in the interview. If this is identified, the research will be stopped and will not continue until the participant is ready. Prods or follow up questions will not be asked if the participant is showing signs of discomfort. The researcher will assess the participant by clarifying if the participant is feeling uncomfortable or distressed during participation in the interview.

B. In the event that any of these potential risks occur, how will it be handled (e.g., compensation, counseling, etc.)?

If significant stress or anxiety is noted, the researcher will stop all research activity and refer to the participant for professional counseling or medical follow up. All counseling, psychological, and medical follow up will be at the participant's own expense.

C. Will this study interfere with any subjects' normal routine?
YES___ NO_***X***__

Because participants are allowed to choose their method of delivery there is more opportunity to work around participant's daily routines and maximize their communication in a method they are comfortable with.

D. Describe the expected benefits to the individual subjects and those to society.

The benefits to the participants is that they will be a part of a growing area of nursing research that is increasing opportunities for students with disabilities. Society will benefit by better understanding a nurse with blindness and their personal experiences. The fact that there are blind nurses being studies will help erase the idea that it is impossible to be a blind nurse.

E. If blood or other biological specimens will be taken please address the following.
Brief Description of Sampled Tissue(s):__***N/A***_____

Describe the personnel involved and procedure(s) for obtaining the specimen(s). Note that the IRB requires that

only trained certified or licensed persons may draw blood. Contact the IRB for more details on this topic.

V. USE OF DATA COLLECTED (Check all that apply)

1. _**X**__Thesis/Dissertation
2. _**X**__Journal Article/Publication/Presentation
3. ___Grant Activities
4. ___ Other : Briefly Describe:_____
   _____

VI. PROJECT CHECKLIST (Attach additional pages as necessary.)

A. Will any investigational new drug (IND) be used? YES___

B. Will any other drugs be used?
YES___ NO_**X**__

If yes to A or B, on a separate page, list for each drug:
1. the name and manufacturer of the drug,
2. the IND number,
3. the dosage,
4. any side effects or toxicity, and
5. how and by whom it will be administered.

C. Will alcohol be ingested by the subjects? YES___

If yes, on a separate page, describe what type and how will it be administered. Refer to the guidelines for administration of ethyl alcohol in human experimentation (OGRD Memo No. 18 available at OGRD).

D. Will the proposed research activity be conducted at an outside (non WSU) facility or entity (such as hospitals, clinics, schools, school districts, factories, offices, etc…)? YES___ NO_**X**__

If yes, the researcher has an obligation to ensure that the outside entity is aware of the proposed research activity and has no objections (i.e. agrees to participate). By signing this application, the researcher indicates that they will comply with this requirement.

In order to respect the sovereign governments, research to be conducted on Native American tribal lands will require a letter from the Tribal Council (or equivalent authorized signatory) to the WSU IRB acknowledging the research activity and their willingness to allow the proposed activity.

FINANCIAL CONFLICT OF INTEREST

Does the researcher or any other person responsible for the design, conduct, or reporting of this research have an economic interest in or act as an officer or director of any outside entity whose financial interest would reasonably appear to be affected by the research?

YES ___ NO ***X***

If yes, please answer the following:

If the economic interest involved is a "significant economic interest" as defined in WSU's Conflict of Interest Policy, has a plan for managing, reducing or eliminating any conflict been established by the Conflict of Interest committee?

YES ___ NO ___

SECTION 2

Is your project EXEMPT?

Exempt Reviews

Federal regulations specify that certain types of research pose very low risks to subjects, and therefore requires minimal review from the IRB. To determine if your project is exempt, answer the following questions.

1. Will subjects be asked to report their own or others' sexual experiences, alcohol or drug use, and will their identities be known to you?
   YES__ NO ***X***
2. Are the subjects' data directly or indirectly identifiable, and could these data place subjects at risk (criminal or civil liability), or might they be damaging to subjects' financial standing, employability or reputation? YES ***X***
3. Are any subjects confined in a correctional or detention facility?
   YES__ NO***X***__
4. Are subjects used who may not be legally competent?
   YES__ NO ***X***
5. Are personal records (medical, academic, etc.) used with identifiers and without written consent? YES__
6. Will alcohol or drugs be administered?
   YES__ NO ***X***
7. Will blood/body fluids be drawn?
   YES__ NO ***X***
8. Will specimens obtained from an autopsy be used? YES__
9. Will you be using pregnant women by design?
   YES__ NO ***X***
10. Are live fetuses subjects in this research?
    YES__ NO ***X***

If you answered YES to any of the questions above, then your project is NOT exempt, but may still qualify for expedited review (see Section 3, Page 7).

If you answered NO to the questions, your research might be EXEMPT if it fits into one of the following categories.

(Circle or Underline all that apply)

1. **Educational Research:** Research conducted in established or commonly accepted educational settings, involving normal educational practices. This is for research that is concerned with improving educational practice.
2. **Surveys, Questionnaires, Interviews, or Observation of Public Behavior.** To meet this exemption, the subject matter must not involve "sensitive" topics, such as criminal or sexual behavior, alcohol or drug use on the part of the subjects, unless they are conducted in a manner that guarantees anonymity for the subjects.
3. **Surveys, Questionnaires, Interviews or Observation of Public Behavior.** Surveys that involve sensitive information and subjects' identities are known to the researcher may still be exempt if: (1) the subjects are elected to appointed public officials or candidates for public office; or (2) federal statute(s) specify without exception that confidentiality will be maintained throughout the research and thereafter.
4. **Archival Research.** Research involving the collection or study of existing data, documents, records, pathological or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects. These data/samples must be preexisting, which means they were collected prior to the current project.
5. **Research Examining Public Benefit or Public Service Programs.** To qualify for this exemption, the research must also be conducted by or subject to review by an authorized representative of the program in question. Studies in this category are still exempt if they use pregnant women by design and their purpose is to examine benefit programs specifically for pregnant women.
6. **Taste Evaluation Research.** Studies of taste and food quality evaluation. Studies of taste evaluation qualify for this exemption only if (1) wholesome foods without additives are consumed; or (2) if a food is consumed that contains a food ingredient at or below the level of and for a use found to be safe.

FINAL QUESTION: Are any subjects under 18 years of age? YES__

If your study uses subjects under 18 years of age, and you plan to use surveys, questionnaires or do interviews, then your project is NOT exempt. All other exemptions apply even if subjects are under the age of 18.

If you answered NO to the questions and your study fits into one of the six categories, then your project is EXEMPT.

SECTION 3

Does your study qualify for EXPEDITED review?

Expedited Reviews

Expedited reviews are for studies involving no more than minimal risk or for minor changes in previously approved protocols. To meet expedited review criteria your protocol must meet the following conditions: no more than minimal risk to the subjects, subjects must not be confined in a correctional or detention facility, and one or more of the following types of participation on the part of subjects.

(Circle or Underline any that apply to your project)

1. **Collection of excreta and external secretions:** sweat, saliva, placenta, and/or amniotic fluid. None of these may be collected by "invasive" procedures, such as those that use cannulae or hypodermic needles, such as in amniocentesis.
2. **Recording of data using noninvasive procedures routinely employed in clinical practice.** This includes but is not limited to the use of "contact" recording electrodes, weighing, tests of sensory acuity, electrocardiography and electroencephalography, and measures of naturally occurring radioactivity.
   This does NOT include procedures which: a) impart matter or significant amounts of energy to the subjects, b) invade the subjects' privacy, or c) expose subjects to significant electromagnetic radiation outside the vis
3. **Collection of hair or nail clippings**, **teeth from patients whose care requires the extraction or collection of plaque and/or calculus** using routine procedures for the cleaning of teeth.
4. **Voice recordings** made for research purposes such as investigations of speech defects and speech pathology.
5. **Moderate exercise** by healthy volunteers.
6. **Experimental research** on individual or group behavior or on the characteristics of individuals, such as studies of perception, cognition, game theory or test development.
   This does NOT include studies...
   ...that involve significant stress to the subjects.
   ...that are intended to produce a relatively lasting change in behavior.
7. Studies of **archived data, records or diagnostic specimens** that are not exempt.
8. Studies involving the **collection of blood samples** by venipuncture, in amounts not exceeding 550 ml (about a pint) in an eight week period and no more often two times per week, from subjects 18 years of age or older and who are in good health and not pregnant.

If your study fits into one of the eight types of participation and required criteria, then your project can receive EXPEDITED REVIEW.

SECTION 4

If your study does not meet exempt or expedited review criteria, then it qualifies for FULL BOARD review.

Full Board Reviews

Protocols that require full board review have the potential for high risks to subjects (physical, psychological or social) or those that have special population consent considerations (research on Native Americans, prisoners, persons who are not legally competent, ethnic considerations).

INVESTIGATOR'S ASSURANCES

This investigation involves the use of human subjects. I understand the university's policy concerning research involving human subjects and I agree...

1. ...to obtain voluntary and informed consent of persons who will participate in this study, as required by the IRB.
2. ...to report to the IRB any adverse effects on subjects which become apparent during the course of, or as a result of, the activities of the investigators.
3. ...to cooperate with members of the IRB charged with review of this project, and to give progress reports as required by the IRB.
4. ...to obtain prior approval from the IRB before amending or altering the project or before implementing changes in the approved consent form.
5. ...to maintain documentation of IRB approval, consent forms and/or procedures together with the data for at least three years after the project has been completed.
6. ...to treat subjects in the manner specified on this form.

Principal Investigator: The information provided in this form is accurate and the project will be conducted in accordance with the above assurances.

Signature_____ Print Name_____ Date_____

Faculty Sponsor: (If P.I. is a student.) The information provided in this form is accurate and the project will be conducted in accordance with the above assurances.

Signature_____ Print Name_____ Date_____

Chair, Director or Dean: This project will be conducted in accordance with the above assurances.

Signature_____Print Name_____Date_____

When Section 1 is filled out and fully signed, review the Packet Checklist (Page 1) to complete the packet for review and submission.

Institutional Review Board: These assurances are acceptable and this project has adequate protections for subjects. This project has been properly reviewed and filed, and is in compliance with federal, state, and university regulations.

Signature_____Print Name_____Date_____

IRB ONLY: This protocol has been given- Exempt___ Expedited___ Full Board___ status.

SECTION 5

DEFINITIONS

ANONYMOUS: Subjects' names are unknown to the investigator, not requested and not given. If the only time the investigator asks for a name is for a signature on a consent form, the investigator should use implied consent, to preserve anonymity.

ASSENT: Agreement by subjects not competent (e.g., children or cognitively impaired people) to give legally valid informed consent to participate in a study.

BENEFIT: A valued or desired outcome to the study that will be an advantage to the subjects participating.

CONFIDENTIAL: Subjects' names are known to the investigator and are usually coded to a master list and/or kept separately from the data and results. This is usually used, for example, when the investigator must match test results with surveys or if there will be a follow-up survey. The investigator has a real need to know subjects' names.

DECEPTION: The protocol is designed to withhold complete information when consent is obtained.

DIRECTLY or INDIRECTLY IDENTIFIABLE: Identities of individual subjects are kept by the investigator. If subjects' identities are inseparable from data, then data are directly identifiable. If subjects' identities are kept separate from data, with information connecting them maintained by codes and a master list, then data are indirectly identifiable. In either case, investigator must assure that confidentiality will be maintained, and must explain how subjects' identities will be protected.

INFORMED CONSENT: Subjects' voluntary agreement, based upon adequate knowledge and understanding of relevant information, to participate in a study or to undergo a diagnostic, therapeutic or preventive procedure.

INTENTIONALLY IDENTIFIED: Subjects' names are to be used in connection with their data when project results are presented to the public. This procedure is common for journalistic-type interview studies, where subjects are public figures or in oral histories. In these cases, the investigator should seek explicit consent from the subjects for the use of their names in connection with their data.

MINIMAL RISK: A risk is minimal where the probability and magnitude of harm or discomfort anticipated in the proposed study is not greater, in and of themselves, than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests. The definition of minimal risk for research involving prisoners differ somewhat from that given for noninstitutionalized adults.

POPULATION: A group of people in society meeting certain criteria to be eligible as subjects in a project's protocol.

PRINCIPAL INVESTIGATOR: The individual (s) with primary responsibility for the design and conduct of a project's protocol.

PROTECTED HEALTH INFORMATION: health information, recorded in any form or medium that is created or received by a health care provider, health plan, public health authority, employer, life insurer, school or university, or health care clearinghouse; and relates to the past, present, or future physical or mental health or condition of an individual; the provision of health care to an individual; or the past, present, or future payment for the provision of health care to an individual."

PROTOCOL: The formal design or plan of a study's activity; specifically, the plan submitted to an IRB for review and to an agency for support. The protocol includes a description of the design or methodology to be employed, the eligibility requirements for prospective subjects and controls, the treatment regimen (s), and the proposed methods of analysis that will be performed on the collected data.

RISK: The probability of harm or injury (physical, psychological, social or economic) occurring as a result of participation in a study. Both the probability and magnitude of possible harm may vary from minimal to significant.

SIGNIFICANT RISK: A study's design that presents a potential for serious risk to the health, safety or welfare of the subjects.

SUBJECTS (HUMAN): Individuals whose physiologic or behavioral characteristics and responses are the object of study in a project. Under the federal regulations, subjects are defined as living individual (s) about whom an investigator conducting a study obtains: data through intervention or interaction with the individual; or identifiable private information.

SECTION 6

FREQUENTLY ASKED QUESTIONS CONCERNING CONSENT PROCEDURES

1. Do I need to get consent? Can I get a waiver from the consent requirements?

If you are using archived data, consent may not be necessary or even possible. Some data do not meet the definition of "archived data," but researchers may still seek a waiver of consent requirements. Only studies with a restricted set of conditions may use this option, and each waiver request is separately reviewed and considered by the IRB.

2. What if I want to give my subjects anonymity?

You should not use a written consent form. Instead you can use a consent script (e.g., phone surveys) or a cover letter (e.g., mail surveys). These documents do the same basic job as a written consent form does informing subjects about the study and their rights. The only difference is that subjects do not sign their name.

3. Do I need to get consent if my project is exempt?

The requirement for some form of consent applies to ALL research, although most exempt projects (particularly mail or phone surveys) can use a consent script or cover letter (for implied consent).

4. What if I audio or video tape my subjects?

You will need to get written consent. The consent procedure needs to specify WHEN the tapes will be destroyed, WHERE they will be stored, and WHO will have access to the tapes. Use a version of the WRITTEN CONSENT FORM.

. What if I want to intentionally identify individuals in my research report(s) (i.e., quote individuals who you interviewed and gave their identities)?

Then you will be required to get their written consent.

6. What if my project is BIOMEDICAL in nature?

Use the sample for written consent forms and the BIOMEDICAL CONSENT FORM CHECKLIST.

7. What are the special consent considerations for children?

If a child is between the ages of 7 and 18, then you should seek both written parental consent and child assent. The assent form language should be at about the same grade level as the child. If the child is between the ages of 3 and 7, then

you should use a VERBAL ASSENT, which is a consent script with language appropriate for the child's age. A child younger than age 3 is considered incapable of participating in the consent process. At all age levels, the final power of consent is usually left to the parents or guardians. More than one age-appropriate assent form may be necessary if the study covers a wide age span.

8. Are there laws that affect the consent process?

   In the course of your research, if you become aware that any specific individual is in imminent danger of harming himself or others (i.e., due to acute depression) or is currently suffering mental or physical abuse, or abusing another individual, you are required by Washington state law to inform the appropriate authorities. If there is a reasonable chance that you may discover such information about your subjects, you must tell them of this requirement when you ask for their consent, because the law requires you to break confidentiality in these circumstances.

SAMPLE CONSENT TEMPLATE SAMPLE CONSENT TEMPLATE SAMPLE CONSENT TEMPLATE

WASHINGTON STATE UNIVERSITY
CONSENT FORM
[TITLE OF ACTIVITY]

Researchers: [List names, academic/staff positions, divisions/departments, telephone numbers of investigators and co-investigators.]

24-hour emergency telephone number with name or position [when relevant, for studies involving more than minimal risk]

Researchers' statement

We are asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions, you can decide if you want to be in the study or not. This process is called 'informed consent.' We will give you a copy of this form for your records.

PURPOSE AND BENEFITS

[Provide a brief background and describe the purpose of the activity. For drug studies, state how many people will be in the study. Describe the expected benefits to individual subjects and/or society. State if subjects will not benefit from being in this study.]

PROCEDURES

[Describe the procedures involved. Include the commitment of time for each, the total amount of time involved, and how long the study will last. As appropriate, specify size of samples to be taken and names and doses of substances to be given. Describe questionnaires, surveys, and interviews and describe or provide examples of the most personal and sensitive questions you will ask. State that subjects may refuse to answer any question or item in any test, inventory, questionnaire, or interview. Include the use of medical, academic, or other records, photographs, audio, or visual recordings.]

RISKS, STRESS, OR DISCOMFORT

[Include information on the psycho-social and physical risks, including side effects, stress, discomforts, breach of confidentiality, or the invasion of privacy that might result from each procedure. Do not state that there are no risks or that risks “should be” minimal. If appropriate, state how side effects will be handled and whom the subject should contact in the event of an adverse reaction. If drugs are used, state that there may be unanticipated side effects. If investigational drugs are used, state that any information developed during the study that might affect subjects' willingness to participate you will provide it to them.]

OTHER INFORMATION

[In studies involving interventions (educational, social, medical, or other) include descriptions of alternative procedures or standard care that are available if a subject chooses not to be in the study. State whether data will be confidential (linked to identifiers) or anonymous (no links). State who or what other agencies will have access to identifiable data. Describe how the data will be used and how long they will be retained. For drug and medical device studies regulated by the U.S. Food and Drug Administration, add: "The U.S. Food and Drug Administration (FDA) reserves the right to review study data which may contain identifying information." State that subjects may refuse to participate or may withdraw from the study at any time without penalty or loss of benefits to which they are otherwise entitled. Include a description of inducements (money, service, course credit) subjects may receive for participation. Indicate what costs subjects may immediately or ultimately have to bear. If applicable, state: "If you are injured as a direct result of study procedures, you will be (cared for by a member of the investigating team OR referred for appropriate treatment)." State who will be responsible for the cost of such treatment. If applicable, state that a copy of the consent form will be placed in the subject’s medical, educational, personnel, or other record.]

MEDICAL RECORDS ACCESS

[In studies involving access to medical records or protected health information include a description of health information to be obtained/collected, how the information will be used, how long it will be retained, who will have access, how the information will be protected and stored and the participant's right to revoke their authorization to access their health information. Authorization to access medical records can be obtained separately from the informed consent.]

Printed name of researcher Signature of researcher
Date

Subject's statement

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have general questions about the research, I can ask one of the researchers listed above. If I have questions regarding my rights as a participant, I can call the WSU Institutional Review Board at (509)335-9661. This project has been reviewed and approved for human participation by the WSU IRB. [If relevant, add: I give permission to the researchers to use my medical records as described in this consent form.] I will receive a copy of this consent form.

Printed name of subject Signature of subject
Date

SAMPLE ASSENT TEMPLATES

Following are two sample assent forms. They are included as guides to you in construction of a child's assent to be used in your project. Fill in the appropriate information and adjust to the specifics of your research.

NOTE:
*Do not include a statement to the effect that "your parent has agreed to allow you to take part in the study". This implies the possibility of parental pressure for the child's participation. Instead use "your parent is aware of this project".
*Make sure you use age appropriate language. For example, do not use the same language for a third grade student as you would a graduate student.

#1

Sample #1 - Minor Assent Document (Ages 7-12)

WASHINGTON STATE UNIVERSITY
ASSENT FORM
[TITLE OF ACTIVITY]

Researchers: [List names, academic/staff positions, divisions/departments, telephone numbers of investigators and co-investigators.]

24-hour emergency telephone number with name or position [when relevant, for studies involving more than minimal risk]

Your parent knows we are going to ask you to ***participate in this project/fill out this survey***. We want to know about kids' ***attitudes/experiences about topic of research***. It will take ***amount of time*** of your time to complete *the task*. Your name will not be written anywhere on the ***research instrument***. No one will know these answers came from you personally.

If you don't want to participate, you can stop at any time. There will be no bad feelings if you don't want to do this. You can ask questions if you do not understand any part of the ***study***.

Do you understand? Is this OK? If you agree to participate, please sign below.

Name (Please print):_____

Signature:
_____

Date: _____

Investigator's Signature:
_____Date:_____

Sample #2 - Minor Assent Document (Ages 13-18)

WASHINGTON STATE UNIVERSITY
ASSENT FORM
[TITLE OF ACTIVITY]

Researchers: [List names, academic/staff positions, divisions/departments, telephone numbers of investigators and co-investigators.]

24-hour emergency telephone number with name or position [when relevant, for studies involving more than minimal risk]

We are doing a research study about purpose in simple language***. A research study is a way to learn more about people. If you decide that you want to be part of this study, you will be asked to*** description, including time involved***.***

There are some things about this study you should know. There are procedures, things that take a long time, other risks, discomforts, etc.

Not everyone who takes part in this study will benefit. A benefit means that something good happens to you. We think these benefits might be description***.***

If you do not want to be in this research study, we will tell you what other kinds of treatments there are for you. This statement applies to research projects that offer treatment or intervention.

When we are finished with this study we will write a report about what was learned. This report will not include your name or that you were in the study.

You do not have to be in this study if you do not want to be. If you decide to stop after we begin, that's okay too.

This study has been reviewed and approved by the WSU Institutional Review Board (IRB). If you have questions about this study, please contact the researcher at *(phone #)*. If you have questions about your rights as a participant, please contact the WSU IRB at 509-335-9661.

If you decide you want to be in this study, please sign your name.

I, _____, want to be in this research study.

(Print your name here)

_____ _____

(Sign your name here) ***(Date)***

Parts in Italics should be modified for your specific project. Other parts may need to be modified as well depending on your research methods.

GUIDELINES FOR COMPOSING A BIOMEDICAL PROJECT CONSENT FORM

Determine if the consent form is going to be written using first person (I) or second person (you). The language should avoid technical medical terminology; use uncomplicated and understandable words. If technical terms must be used, clearly explain in simple language. (e.g., Placebo is an inactive medication or "sugar pill" or a placebo contains no medication.) Consider attaching a glossary of terms. The consent form should be tailored to the particular procedure and participant, avoiding irrelevant references, gender confusion, etc. The name of the investigator and telephone number should appear in the consent form.

BIOMEDICAL CONSENT FORM CHECKLIST

__Title of study
__Investigator name, title and phone number
__Investigator affiliation

HEADINGS FOR CONSENT FORM

Introduction
__Description of the study
__Role of participant

Purpose
__What is being studied
__Why it is being studied
__Purpose of research
__Indicate experimental/research

Procedures
__List of all procedures
__Intervals of procedures
__Length of time participant in study

Participation/Withdrawal
__What will be given or received and how administered
__Length of hospital stay, if required
__Prior experience with drug or device

Reimbursement/Compensation for Illness/Injury During Study
__Name/phone number of treating doctor
__Where will treatment be given
__Other forms of compensation, if any

Confidentiality
__Indicate records are confidential
__Safeguards used if data published
__Who will have access to records

Patient Rights
__Name/phone number of investigator
__Listing of WSU IRB (509) 335-9661

Voluntary
__Statement regarding voluntary participation
__Statement regarding withdrawal by participant during study

Risks
__Describe all risks in detail
__Describe all possible side effects (in consent form or as attachment)

Benefits to Participant
__Describe in detail
__State if none

Alternative Treatment/Procedures
__Describe in detail

Exclusions for Nonparticipation
__Describe in detail

Participant Costs/Payment
__Payment to be received by participant
__Costs to participant, if any
__Insurance coverage, if any

__Statement regarding withdrawal of participant by physician

Legal Rights/Patient Consent
__Statement regarding legal rights

__All questions answered
__Emergency phone number
__Copy of consent form given to participant

__Signature and date line for participant (or guardian)

__Signature and date line for investigator

__Signature and date line for witness

Other
__Written in first person/second person

__Technical medical terminology explained