

CRITICAL CARE NURSES' PERCEPTIONS AND KNOWLEDGE OF
PATIENT CONFIDENTIALITY

Angela Beth Newman

A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the School of Nursing.

Chapel Hill
2011

Approved by:

Diane Kjervik, JD, RN, FAAN

Edward Halloran, PhD, RN, FAAN

Susan Letvak, PhD, RN

Richard Redman, PhD, RN

Marcia Van Riper, PhD, RN

©2011
Angela Beth Newman
ALL RIGHTS RESERVED

ABSTRACT

ANGELA BETH NEWMAN: Critical Care Nurses' Perceptions and Knowledge of Patient Confidentiality
(Under the direction of Dr. Diane Kjervik)

The perceptions that critical care nurses express regarding patient confidentiality may yield insight to what information this population of nurses' value as protected health information, their knowledge of confidentiality law and bio-ethics and what information they communicate with patients' family members and others visitors. The purpose of this study was to explore critical care nurses' perceptions and knowledge of patient confidentiality. In an effort to explore this, 12 respondents were asked (a) what knowledge of legislation and ethics critical care nurses have related to confidentiality (b) how critical care nurses describe their roles regarding patient confidentiality and its application in their work environment, and (c) how critical care nurses describe their roles regarding confidentiality in the intensive care unit (ICU)?

For this qualitative study, a naturalistic inquiry methodology was employed using semi-structured interviews and two structured scenarios that elicited participants' feelings and probable actions related to the scenarios. Participants were recruited via snowballing. Interviews were audio-recorded, and transcripts were analyzed using content analysis, within case and cross-case.

The synthesizing framework, Therapeutic Jurisprudence provided structure for the study, allowing assessment of the actors (nurses) and the application of rules (legislation) in

relation to the outcomes of application of the rules to individual practice (therapeutic vs. anti-therapeutic).

Critical care nurses were knowledgeable about federal confidentiality law, the role of the Board of Nursing and resources available regarding confidentiality. Further education for critical care nurses about specific state legislation as well as organizational policy is needed. Nurses employed their knowledge and values regarding confidentiality in the interaction and communication with their patients, family members and visitors. Nurses' application of ethical principles exemplifies their concern regarding the communication they *should* provide and the information they *desired* to provide to patient families and significant others. Nurses indicated that while the legislation is therapeutic, there is still work needed to prevent breach of confidentiality.

Understanding the critical care nurse's perception and knowledge may lead to adjustments in decision making regarding the protection of health information. Re-examination of health care policy at all levels may be better operationalized for nurses in the critical care field of practice.

DEDICATION

I dedicate this dissertation foremost to my **Lord and Savior, Jesus Christ**. It is through His grace and love by which I am saved. Second, this work is dedicated to my family. To my parents, **Ronald R. Newman** and **Kathy M. Newman**, who have been my motivation, cheerleaders, support, and confidants. They have provided for, supported and nurtured my education since kindergarten. They encouraged me and believed in me, even when I was discouraged and ready to give up. They have provided unconditional love and guidance throughout my life and molded me into who I am today. Words cannot express the depth of my gratitude for all that my Mom and Dad have done for me.

I dedicate this work to my grandparents, three of whom are rejoicing for me from Heaven. I miss you all deeply. To my late PawPaw, **Drewey R. Newman** whose advise and wisdom were valued beyond measure. He couldn't wait to see me be an official Tarheel. To my Grandma **Hattie L. Newman**, your strong value of education and encouraging words to get all the education I could served as fuel for my desire to pursuit a PhD. I won't ever forget your words of encouragement and prayers as I worked to finish my "dysentery." To my late Grandparents **Harold R. and Louse L. Marsh**, their never-ending love and pride in me served as a source of inspiration.

It is with the love and support of my sisters that I have been able to complete this conquest. **Marsha N. Payne, Amy M. Newman and Amanda N. Farmer**, you all mean more to me than you'll ever know. For all those times that I couldn't go out and play because

of school, I've got my homework done now and can't wait to spend many hours catching up playing cards and going shopping. To my brother-in-laws, **Bruce W. Payne** and **Dallas R. Farmer**, thank you for your words of encouragement and support. To my niece **Jozalina E. Payne (Jozie)** and all my future nieces and nephews, I hope that my example of hard work and perseverance serves as an inspiration that you can "do all things through Christ."

To my friend **Angie H. Seaford**, your genuine friendship has been truly a blessing since the beginning of our nursing school days. Thank you for all of your support and prayers throughout the years, it has meant more to me than you can know. To all of my "2100" friends, your friendly cheers of encouragement and friendship throughout my educational pursuits have meant so much to me.

To my mentor, **Diane Kjervik, JD, RN, FAAN**, thank you for your understanding and patience throughout my journey through this program. You have led me, advocated for me, encouraged me and gently pushed me to achieve things I didn't believe possible. I look forward to a continued professional and collaborative relationship in the future. In conclusion, I dedicate this work to all critical care nurses. Your dedication to our patients, their families and the profession of nursing is amazing. I look forward to working with you in furthering our mutual goal of advancing the art and science that is critical care nursing.

ACKNOWLEDGEMENTS

It is my pleasure and honor to acknowledge those who have made the completion of my doctoral education both pleasurable and fruitful. First, with the constant and supportive guidance of my dissertation chair, **Diane Kjervik, J.D., R.N., F.A.A.N.**, this journey has afforded me the opportunity to grow professionally as a nursing scientist but also as an advocate for the profession and art of nursing. Diane, I will be forever grateful for your encouragement and thoughtful acts of caring and kindness. It has truly been a pleasure having had the privilege of your coaching and mentorship throughout the years. Your passion for nursing and the therapeutic impact of legislation on the provision of ethical care has been truly inspirational.

To the members of my dissertation committee—**Drs. Edward Halloran, Marcia Van Riper, Richard Redman and Susan Letvak**, thank you for your support of my research interest and endeavor. You freely shared your creative ideas, your time and dedication and for it I am sincerely grateful. I am truly blessed to have had the privilege of your guidance and support throughout the completion of my doctoral study. Your dedication to my educational journey and that of others is deeply appreciated.

I would like to express my gratitude to the faculty and staff of The University of North Carolina at Chapel Hill, School of Nursing. It is with the help of these dedicated individuals that I and many others have been able to successfully and seamlessly complete our studies. To those critical care nurses who participated in this study, your passionate

dedication to the profession, your patients and their families is evident by your eager participation in furthering the profession through inquiry; Thank you.

To my friends and colleagues at The University of North Carolina at Greensboro, your kind words of encouragement are sincerely appreciated. **Dr. Elizabeth Van Horn**, I will be forever grateful for your words of encouragement, motivational cheers and late night chats. **Dr. Susan Letvak**, it is with heartfelt gratitude that I thank you for your belief in me throughout the years. Your belief in me personally and professionally encouraged me to pursue a PhD in Nursing. Words cannot truly express how much your constant reassurance and words of encouragement have meant to me. You have truly made reaching the finish line even sweeter.

Finally, I would like to acknowledge the ever-present support, guidance and love that my family and friends have offered throughout this process. Your words of kindness, thoughtfulness and prayers were more appreciated than you can ever know.

TABLE OF CONTENTS

LIST OF TABLES	xii
----------------------	-----

Chapter

I.	CRITICAL CARE NURSES' PERCEPTIONS AND KNOWLEDGE OF PATIENT CONFIDENTIALITY	1
	Background Information	5
	Definitions and Critical Attributes	6
	Legal Components of Patient Confidentiality	10
	Ethical Perspectives of Patient Confidentiality	14
	Relationship between the Law and Ethics	16
	Significance to Critical Care Nursing	17
	Assumptions	19
II.	REVIEW OF LITERATURE	20
	Related Literary Support and Research	21
	Federal Legislative Support for Protection of Health Information	32
	North Carolina State Legislative Support for Protection of Health Information	35
	Case Law Support for Protection of Health Information	37
	Legislative Support for Release or Breach of Protected Health Information	40
	Case Law Support for Release or Breach of Protected Health Information	41

Synthesizing Framework	43
Research Questions.....	49
Impact of this Study	50
III. METHODOLOGY	51
Purpose and Problem Statement	51
Research Design.....	52
Participants.....	52
Setting	54
Protection of Human Subjects	54
Procedure	54
Data Management and Analysis	56
Trustworthiness.....	60
IV. FINDINGS.....	61
Research Question 1: What Knowledge of Legislation and Ethics Do Critical Care Nurses Have Related to Confidentiality?	62
Research Question 2: What Observations Do Critical Care Nurses Have Regarding Patient Confidentiality and its Application in Their Work Environment?.....	75
Research Question 3: How Do Critical Care Nurses Describe Their Roles Regarding Confidentiality in the ICU?.....	83
Summary	84
V. DISCUSSION AND CONCLUSIONS	86
Discussion	86
Research Question 1: What Knowledge of Legislation and Ethics Do Critical Care Nurses Have Related to Confidentiality?	87

Research Question 2: What Observations Do Critical Care Nurses Have Regarding Patient Confidentiality and its Application in Their Work Environment?	94
Research Question 3: How Do Critical Care Nurses Describe Their Roles Regarding Confidentiality in the ICU?	98
Implications.....	99
Limitations	102
Conclusions.....	103
APPENDICES	105
REFERENCES	118

LIST OF TABLES

Table

1.	Participant Demographics	55
2.	With-in Case Data Matrix Display	58
3.	Across Case Data Matrix Display for Responses to Vignette #1	59
4.	Participant Perceptions of What is and is Not Confidential.	66
5.	Participant Perceptions of Available Confidentiality Resources	73

CHAPTER 1

INTRODUCTION

Since the early years of the nursing profession, nurses have been widely known as those who selflessly help others through times of distress. Holistic care of the patient and family has, also historically, been a driving force in the field of nursing. Therefore, incorporating the family and those others deemed family by the patient has become a standard of care in today's healthcare setting (Andershed & Ternestedt, 2000; Daley, 1984; De Jong & Beatty, 2000; Dimond, 1999; Dracup & Bryan-Brown, 2004; Gelling & Prevost, 1999; Henneman & Cardin, 2002; Paladichuk, 1998; Quallich, 2002; Roberts, 2003). However, this task can be difficult when trying to balance between the fine lines of maintaining patient confidentiality and incorporating a support network of friends and family into the care of the patient. This balancing act becomes even more difficult in critical care settings where patients and families often need each other most. It is for this reason that further research is warranted to explore the research question "What are critical care nurses' perceptions and knowledge of patient confidentiality?"

Medicine has long held that information regarding the patient, whether connected to professional practice or not remain secret (American Medical Association [AMA], 2001; Applebee, 2006). The Nightingale Pledge, while not written by Florence Nightingale but named out of respect for her contributions to nursing, addresses the nurses' responsibility to hold information related to the patient in confidence (American Nurses Association [ANA],

2011). These principles of patient confidentiality both in nursing and medicine were derived from the Hippocratic Oath, originally written in the fourth century B.C. (AMA, 2001; Applebee, 2006; North, 2002). This confidential relationship between patients and nurses is usually built on trust that nurses seek to provide safe, high quality care, including the protection of confidential health information. Without trust in the nurse/patient relationship, clients might withhold confidential information from the nurse or other members of the healthcare team. Lack of information can impede the provision of the highest quality care for the client (Cochran, 1999; Ellenchild-Pinch, 2000; Knopp & Satterlee, 1999; Meer & Vandecreek, 2002; Rivas & Sulmasy, 2002; Snider & Hood, 2001; Trueman, 2000; Whetten-Goldstein, Nguyen, & Sugarman, 2001).

Because of the intense environment and the role of the nurse as information giver yet protector of confidential health information, it is important to understand the critical care nurse's perception and knowledge of health care confidentiality. For the purposes of this study, critical care is defined as adult health critical or intensive care units, excluding emergency rooms and post-anesthesia care units (PACU). In critical care units, patients, families and health care professionals face dilemmas daily involving the confidentiality of health information. Often, patients are incoherent or physically unstable and thus unable to interact with their families and/or to make autonomous decisions regarding their confidential health information. Families, out of love and concern, have a need and desire to know information about their relatives. This need for information can become complicated for patients, families and health care workers due to confidentiality legislation and codes of ethics. Family members have a desire to know information, and healthcare workers are often torn between the law, principles of bioethics, professional codes of ethics and their own

personal values and beliefs. Federal legislation, the Health Insurance Portability and Accountability Act (HIPAA), allows for information to be released “*in loco parentis*” (Latin for “in the place of a parent”) to family members (Legal Dictionary, 2008). This could potentially further confusion, as families or critical care nurses then have to decide who “*in loco parentis*” encompasses (Cochran, 1999; Daley, 1984; Dracup & Bryan-Brown, 2004; Henneman & Cardin, 2002; Quallich, 2002; Roberts, 2003; Uses and Disclosures of Protected Health Information: General Rules, 2002).

During a critical illness, family members of critically ill patients potentially face unfamiliarity. They are often unfamiliar with their rights, the many definitions of confidentiality and how confidentiality applies to their context. Even if families of critical care patients are familiar with HIPAA and state law, they are often unfamiliar with unit and hospital procedures, policies and application of these to their situation. Patients and family members also face unfamiliarity of staff. Staffing assignments change frequently; often there is inconsistency in application and interpretation of the concept of confidentiality, confidentiality legislation, codes of ethics and individual institutional policy regarding patient confidentiality among staff members (Henneman & Cardin, 2002; Karro, Dent, & Farish, 2005; Knopp & Satterlee, 1999; Kowalski, Lawson, & Oelberg, 2003).

Visitation with family members in critical care units poses a dilemma for family members of critical care patients as well as critical care nurses. During this stressful time, information as well as comfort provided by visiting their loved ones aid in the coping process. There is a large movement for family centered care in critical care units. Family members want to be at the bedside to participate in patient care, but also to continue communication and information flow. Confidential interaction and communication during

visitation hours can be dependent on the physical characteristics of the unit design (Dracup & Bryan-Brown, 2004; Henneman & Cardin, 2002).

The physical design of critical care units (open v. individual private rooms) also creates dilemmas for patients, families as well as nurses. If the unit is one of open design, meaning patients are separated only by curtains, then each time staff needs to speak with a patient's family, they must leave the bedside to have confidential conversation.

Conversations with patients in an open critical care unit are difficult to maintain confidential. Patients cannot be moved to other areas to partake in discussion or avoid overhearing confidential information. Conference rooms are not always available for confidential conversation; this leaves medical staff to discuss patient information in any available and "somewhat" private area. Open design critical care units also negate patient privacy during emergency situations. These situations are unpredictable and families are often present on the unit when they begin. Asking family members to leave during these crises only reinforces the knowledge that their family members' privacy is also compromised. Individual private rooms in critical care units are most beneficial in promoting confidential interaction and conversation with patients and their families. Private rooms are only as effective as the health care provider in promoting confidentiality in critical care units (Dracup & Bryan-Brown, 2004; Henneman & Cardin, 2002; Karro et al., 2005; Knopp & Satterlee, 1999). Paladichuk (1998) maintains that open access critical care units are beneficial in promoting family involvement in patient care and education. She notes that confidentiality in critical care units is "tricky." She notes that families talk about their family members "story" in the waiting room, and curiosity by non-family members is natural as they develop relationships and care for other patients during the length of stay in the hospital setting.

These aspects, familial unfamiliarity, dilemmas, visitation and physical environment of critical care nursing have impacted my own personal practice as a critical care nurse and may impact other critical care nurses' experiences surrounding patient confidentiality and their perceptions of patient confidentiality. Critical care nurses' perceptions of confidentiality and their knowledge of confidentiality law and ethics may influence their actions for protection of physical and non-physical privacy and confidentiality and may also affect the nurse-patient-family relationship. Relationships between health care providers and recipients must be built on trust and confidence that personal information will remain confidential. Without trust, full disclosure of critical information may not occur and may negatively impact the provision of care (AMA, 2011; Cochran, 1999; Dracup & Bryan-Brown, 2004; Henneman, 2002; Karro et al., 2005; Knopp & Satterlee, 1999; Paladichuk, 1998; Quallich, 2002). The way that nurses' views of confidentiality affect patient care is the focus of this study.

Background Information

American law and codes of ethics have long supported protection of privacy and confidentiality since 1890, when Samuel D. Warren, a U.S. attorney, became embarrassed by extensive and detailed publication of his wife's social gatherings. He and his law partner Louis Brandeis proposed the invasion of privacy tort. He stated in a *Harvard Law Review*,

common law has always recognized a man's house as his castle, impregnable, often even to its own officers engaged in the execution of its commands. Shall the courts thus close the front entrance to constitutional authority, and open wide the back door to idle or prurient curiosity? (Warren & Brandeis, 1890, p. 220)

This review casts light on what would become one of the largest legal and ethical issues of the twentieth century.

Over time, The Privacy Act of 1974 was enacted at the federal level. The Act mentions individual medical records and requires methodology to manage all records containing medical information as well as requiring procedures for notification of disclosure of medical information (5 U.S. Code § 552a). Protection of health information became a national incentive under the George H. W. Bush administration in the 1990s and continued through the Clinton administration. HIPAA was enacted as P.L.104-191 in 1996. Final regulations were accepted in 2000 and recorded in the Code of Federal Regulations (C.F.R.) title 45 §§ 160- 164. Compliance by those affected was required by April 14, 2003. This legislation, administered by the U.S. Department of Health and Human Services (DHHS), Office for Civil Rights, provides a legal minimum standard to protect the privacy and confidentiality of health care recipients. HIPAA preempts state law when state law is less restrictive about privacy and confidentiality of health information (Erickson, 2005; Erlen, 2004; Flores & Dodier, 2005; Harman, 2005; Kelly et al., 2002; Kuczynski & Gibbs-Wahlberg, 2005; Office for Civil Rights, 2011; Owen, 2000; Preemption of State Laws: General Rules and Exceptions, 2002; Roberts, 2003).

Definitions and Critical Attributes

Confidentiality is broadly defined as a promise not to reveal private, secret or intimate information to third or more parties outside of the confidential relationship (Beauchamp & Childress, 2001; Furrow, Greaney, Johnson, Jost, & Schwartz, 2001). Other definitions are more specific detailing that confidentiality is a contract or promise between two or more parties not to reveal information to a non-included party (Beauchamp & Childress, 2001; Furrow et al., 2001). Confidentiality or the term confidential is applicable in many professions and situations. In medicine, nursing and religion confidentiality legally means

privileged communication that is almost impenetrable. When a privilege exists between the client and the professional, the information learned or obtained during interactions is private, non-disclosed and protected from discovery except under special mitigating circumstances (AMA, 2011; Beauchamp & Childress, 2001; Derse, 1999; Knopp & Satterlee, 1999). There are legal as well as ethical definitions of confidentiality. The law defines confidentiality as a right to privacy. Confidentiality is a legal obligation to abide by the standards set forth by federal as well as state legislation (Declaration of Patient Rights, 1997; Public Welfare, 2000). The law allows for few exceptions to this right of privacy as outlined by HIPAA and individual state laws. The concept of confidentiality is also an ethical obligation. An ethical definition of confidentiality is a moral expectation or promise of secrecy among involved parties about certain information or circumstances. When information is disclosed by one individual to another, with the promise to hold the information private, the promise is honored. Ethical definitions for the term confidentiality are derived from basic ethical principles of autonomy, beneficence, non-maleficence as well as ethical theory and individual virtues (values and beliefs) (AMA, 2011; Beauchamp and Childress, 2001; Derse, 1999; Knopp & Satterlee, 1999).

Many characteristics of confidentiality, both legal and ethical, are applicable in clinical settings. A primary critical attribute of confidentiality is communication. Information flow between health care providers and recipients is essential, whether that communication be oral, physical, written or electronic. Communication of confidential information requires a sense of trust among those privy to the communication based on a promise or contract between all involved to keep the information private. Information is a critical core of

confidentiality. Whether the information is business related (trade secrets, personnel files) or health related, without information, no need for confidentiality exists (Quallich, 2002).

Another aspect of confidentiality that is critical in clinical settings is trust between the involved parties. Relationships between health care providers and recipients must be built on trust and confidence that personal information will remain confidential. Without trust, full disclosure of critical information may not occur and may negatively impact the provision of care. Confidentiality in clinical settings invokes requirements of the physical setting. The use of private patient rooms, barrier curtains, closed doors and strict control of medical records are all essential in maintaining client confidentiality (AMA, 2011; Cochran, 1999; Dracup & Bryan-Brown, 2004; Henneman & Cardin, 2002; Karro et al., 2005; Knopp & Satterlee, 1999; Quallich, 2002).

Integrity and professionalism are critical attributes to confidentiality in clinical settings. Good moral character, honesty and adherence to ethical and legal principles and the promise of confidentiality are essential. Fidelity to each of the parties involved in confidential interactions is also critical. Fidelity to the contract or promise and consistency in interactions, communication and applicability of the promise is necessary for confidentiality to exist. Without integrity, fidelity and consistency, a lack of trust will develop and taint confidential relationships (Applebee, 2006; Cochran, 1999; Henneman & Cardin, 2002; Knopp & Satterlee, 1999; Quallich, 2002).

Along with integrity, fidelity and consistency, critical to confidentiality in clinical settings is prudence and discretion. Good judgment is critical when health information is shared. Should a client disclose intent to harm an innocent third party, or clinical data

presents a public health threat, prudence and discretion by the health care provider is essential for adherence to legal and ethical perspectives of confidentiality (Quallich, 2002).

As much as good judgment is a critical attribute of confidentiality, compassion and understanding of clients and their families is also essential. Compassion for the context of the situation and understanding of families need for information are part of prudence and discretion. Exemplifying compassion and understanding may assist coping within families in respect of protecting confidential information. Strict adherence to the law is required to prevent penalty. Strict adherence, combined with compassion and understanding of the context of the clinical setting may alleviate fear, mistrust and misinterpretation of actions and interactions of health care providers between health care recipients and their families. Appreciation of individual values and beliefs, as well as adherence to ethical and legal principles and the promise of confidentiality are essential in critical care nursing (Applebee, 2006; Cochran, 1999; Henneman & Cardin, 2002; Knopp & Satterlee, 1999; Quallich, 2002).

Minimum standards, set by legal and ethical perspectives are also critical to confidentiality. Without minimum standards, definitions and application of confidentiality would rely upon individual values and beliefs. Chaotic interpretation of these individual definitions and application of confidentiality would lead to mistrust, misunderstanding and fear of health care providers having a detrimental effect on provider-client relationships. In an effort to minimize chaotic interpretation and application of confidentiality, it is imperative to begin to understand critical care nurses' understanding and knowledge of the concept of confidentiality.

Legal Components of Patient Confidentiality

Individual state boards of nursing address the concept of holding patient information confidential. According to the North Carolina State Board of Nursing (BON), in Rules for RNs and Components of Nursing Practice for the Registered Nurse (21 NCAC § 36.0024 (g) (4), 2002), registered nurses are to “safeguard confidentiality.” Protection of health information about healthcare recipients is addressed in the Declaration of Patient Rights (1997). NC legislation requires that all patients receive notification upon admission of their rights as patients and the patient bill of rights be publicly displayed in all facilities (Notice to Patients, 1983). NC statutes regarding confidentiality are considerably general and do not explicitly define the maintenance of confidential patient information. Federal legislation preempts NC state law in this instance and therefore, healthcare workers and other covered entities must defer to federal law when in need of legislative guidance for protection of information about health care recipients.

NC legislation supports the protection of information about health care recipients as well as communication with the recipients. The general statute recognizes the need for nurse-patient privilege and indicates that no disclosure of patient-nurse communication should occur, except under direction of a superior or district court judge for purposes of justice (Nurse Privilege, 2004). In 2006, legislation was enacted that waived the physician-patient and nurse-patient privilege in instances of child abuse and disclosure of information related to impaired driving accident cases (Physician-patient & Nurse Privilege Waived in Child Abuse; Disclosure of Information in Impaired Driving Accident Cases, 2006).

Legal protection of information about health care recipients is supported by federal legislation through HIPAA. The federal legislation requires patients, upon admission to

health care facilities, to specify with whom and what confidential information may be shared. Most institutions interpret and apply this federal legislation by giving the patient the opportunity to declare their wishes regarding their confidential health information during the admission process. Patients often sign a blanket confidentiality clause that allows institutions to share confidential health information with anyone who asks about the patient by name. However, not all patients are capable of comprehending this information, during the admission process. In the critical care unit setting, the patient's condition often precludes the nurse's ability to establish communication with the patient and therefore inhibits the nurse's ability to determine the patient's wishes regarding their confidential health information.

The details of HIPAA legislation are complex and often times confusing. Along with federal as well as individual state legislation regarding confidentiality, there are obligations not only to individual personal convictions and values, but to professional codes of conduct and codes of ethics. The patient populations, within which critical care nurses practice offers a multitude of situations that require the critical care nurse to know, comprehend and implement governing legislation.

Within the legislation, there are key terms and definitions that are imperative for a critical care nurse to understand. Agents and agencies affected by HIPAA are declared covered entities. The privacy rule regulates the access, usage, sharing and storage of protected health information (PHI). HIPAA supports confidentiality through standards of accountability for covered entities with access to PHI including healthcare workers, agencies, organizations (public and private), healthcare clearinghouses, health plans, government agencies, private businesses and essentially any person or organization who has access to PHI (Clark, 2004; Definitions, 2006; Erickson, 2005; Erlen, 2004; Flores & Dodier, 2005;

Harman, 2005; Kuczynski & Gibbs-Wahlberg, 2005; Lucas & Adams, 2004; Office for Civil Rights, 2011; Roberts, 2003; Yang & Kombarakaran, 2006).

The privacy rule governs the use and disclosure of PHI; any information, whether oral, written or electronic that is specific to a client is considered PHI. Examples of protected health information are demographic data, diagnoses, treatments and payment information. The definition of PHI includes billing information as well as insurance claims (Clark, 2004; Erickson, 2005; Erlen, 2004; Flores & Dodier, 2005; Harman, 2005; Office for Civil Rights, 2011; Roberts, 2003; Uses and Disclosures to Carry Out Treatment, Payment, or Health Care Operations, 2000).

There are circumstances in which legal and ethical principles support disclosure of PHI. Often the decision to disclose or not disclose PHI requires quick thought and action, without the benefit of time for legal analysis or ethical debate. HIPAA allows for disclosure of information in many, specific instances, particularly applicable to critically ill patients. In the instance of emergency or incapacity, healthcare workers may use their professional judgment in regard to disclosure of information (Uses and Disclosures for Which an Authorization or Opportunity to Agree or Object is Not Required, 2002; Uses and Disclosures Requiring an Opportunity for the Individual to Agree or to Object, 2000). HIPAA does not require that every risk of disclosure of PHI be eliminated. Federal legislation does not impugn the incidental disclosure of information as long as reasonable effort and measure was taken to prevent the disclosure and the disclosure was minimally necessary (Affirmative Defenses, 2009; Definitions, 2009; Office for Civil Rights, 2011; Uses and Disclosures of Protected Health Information: General Rules, 2002).

Information that has been de-identified (the identifiable information has been removed) may be released as necessary without restriction. Information may be released to the individual and/or their representative and they retain the right to agree or oppose the release of their protected information (Office for Civil Rights, 2011; Uses and Disclosure of Protected Health Information: General Rules, 2002).

Two reasons for disclosure of PHI are for public interest and benefit (Uses and Disclosures for Which an Authorization or Opportunity to Agree or Object is Not Required, 2002). These reasons are prominent in critical care units. Often patients are admitted to critical care units with community acquired diseases or potentially communicable diseases. As defined by federal and state legislation, PHI may be released to officials in prevention or control of communicable illness. Release of information is permitted to individuals who may have been exposed or have contracted a communicable disease. Release of information may be required as directed by the Food and Drug Administration (FDA) as well as to employers in circumstances of work-related injuries or medical situations which require monitoring as governed by the Occupational Safety and Health Administration (OSHA). Disclosure of information is required in instances of abuse, neglect or domestic violence, judicial and administrative proceedings and for law enforcement purposes. Information may be released without consent to funeral directors, coroners and medical examiners as necessary for identification of decedents, examinations and other duties of these professionals. Disclosure of protected information is mandated for essential government functions and for serious threats to the health and safety of others (Office for Civil Rights, 2011; Uses and Disclosures for Which an Authorization or Opportunity to Agree or Object is Not Required, 2002).

Breaches of confidentiality are defined as the intentional or unintentional disclosure of PHI and can lead to financial and criminal repercussions. U.S. Code (U.S.C.) title 42 § 1320d-6, Wrongful Disclosure of Individually Identifiable Health Information, indicts civil penalty up to \$250,000, but also criminal penalty up to 10 years imprisonment, dependent on the intent and use of the individually identifiable health information. Within the profession of nursing, breaches of confidentiality are also handled by disciplinary hearings conducted by the Board of Nursing and are considered a civil act, as opposed to federal legislation which makes breach of confidentiality a criminal act in addition to civil. Repercussions of breach of confidence from the State Board of Nursing could include suspension or loss of licensure (Components of Nursing Practice for the Registered Nurse, 2002). Given the gravity of the requirements, it is ever more imperative to investigate the critical care nurse's perception of patient confidentiality and their knowledge of the applicability of the concept of confidentiality as well as legal and ethical obligations to the practice of nursing.

Ethical Perspectives of Patient Confidentiality

Ethical principles also serve to protect information about health care recipients. Virtually all health care professional organizations and institutions publish a code of ethics. The two most applicable organizational codes of ethics for medicine and nursing are addressed by the AMA and the ANA (AMA, 2011; ANA, 2001). Holding patient information as confidential is addressed in the Florence Nightingale Pledge, "I will do all in my power to maintain and elevate the standard of my profession, and will hold in confidence all personal matters committed to my keeping and all family affairs coming to my knowledge in the practice of my calling" (ANA, 2011, para. 2). Often, principles of bioethics, autonomy, non-maleficence, beneficence and confidentiality are taught in medical ethics courses. Each of

these principles can be used to address the protection as well as the disclosure of information about health care recipients (Burkhardt & Nathaniel, 2008; Furrow et al., 2001).

The principle of autonomy allows individuals to determine their own actions and decisions regarding their own selves. Autonomy demands respect of persons and encourages individuals to control their own PHI. Respect of autonomy supports the individuals' right to confidentiality of their healthcare information as well as disclosure of information, if the individual makes their own decision. Autonomy requires that health care workers respect of the patient's ethical right to disclose or not disclose PHI (Burkhardt & Nathaniel, 2008; Furrow et al., 2001).

Non-maleficence is described as the do no harm principle (Burkhardt & Nathaniel, 2008; Furrow et al., 2001; Iserson, 1999). This principle is described in the Hippocratic Oath as well as many codes of ethics (North, 2002). The idea of non-maleficence promotes the decision to hold protected health information in confidence in an effort to prevent harm to health care recipients. Information should not be released, as disclosure may cause psychological, physical or emotional harm to the health care recipient. Release of confidential information may invoke harm or threat to an individual's autonomy, but it also may be harmful to keep information secret. In cases of communicable disease, legal obligation allows for disclosure of information, the principle of non-maleficence applies to these situations for protection of or preventing harm to others.

The principle of beneficence indicates a duty to promote another's well-being. Beneficence is applicable to protection of health information in an effort to promote and preserve the individual right to privacy, to maintain their dignity and to autonomy. Distributive Justice would hold that information about health care recipients should be

confidential based on the equitable distribution of benefits versus risk. This principle states that society should have equitable distribution of materials and can be further extended to information in this instance. This principle holds that no one individual or group hold more benefit or risk than any other group. If society is benefited by keeping information about health care recipients confidential, the principle of distributive justice advocates protection of information (Burkhardt & Nathaniel, 2008; Furrow et al., 2001; Iserson, 1999).

Relationship between the Law and Ethics

There are many defining characteristics associated with confidentiality. Some of the characteristics are common in both ethical and legal perspectives of confidentiality. Both legal and ethical perspectives imply a sense of duty; a legal duty to follow the letter of the law and an ethical obligation to follow ethical principles and uphold professional codes of ethics. The law imposes civil and criminal punishment for dereliction of this duty. An ethical breach of confidentiality is a breach of professional codes of ethics and disciplinary action may include loss of licensure and fines. Both contexts are associated with case law. Often legal precedent is set by situations that arise from differing views of what actions are morally right or wrong in health care. The right to die and duty to warn are examples of ethical issues that lead to legal battles.

The legality of confidentiality comes from a right to privacy as defined by the U.S. constitution, federal and state legislation. Ethical perspectives of confidentiality are based on ethical principles, theory and individual morals, values and beliefs. Confidentiality from a legal perspective sets forth formal societal rules and requires specific actions. Ethical approaches to confidentiality are flexible, situation based and adaptable to many situations. The ethical principle of confidentiality is easier to mold to the needs and circumstances of

medical ethics as opposed to the law. Laws about confidentiality are difficult to make, change and are rigid to apply to medical situations. Confidentiality and privacy legislation is often complicated and difficult to interpret. Often, the law requires an attorney or judicial opinion to interpret. Ethical standards of confidentiality are interpretable by bedside practitioners and only in extreme cases involve medical ethics committees or outside interpretation. Ethical approaches value relationships and seek resolution with beneficence and non-maleficence for all involved parties (AMA, 2011; Beauchamp & Childress, 2001; Derse, 1999; Iserson, 1999; Knopp & Satterlee, 1999; Quallich, 2002).

Both legal and ethical perspectives of confidentiality require protection of private information. Both demand respect of the patient's right to autonomous decision making. Both also require fidelity. Legal perspectives require fidelity to the letter of the law and ethical perspectives to codes of ethics and professionalism (AMA, 2011; Applebee, 2006; Beauchamp & Childress, 2001; Derse, 1999; Iserson, 1999; Knopp & Satterlee, 1999; Quallich, 2002).

Significance to Critical Care Nursing

There are circumstances in which critical care nurses may be called upon to evaluate whether information should or should not remain confidential. On occasion, the critical care nurse may find him or herself in situations when decisions regarding protected health information require quick action, without the benefit of time for legal analysis or ethical debate. HIPAA requires protection of certain health information, but also allows for disclosure of information in many, specific instances particularly applicable to the critical care population. The gravity of decisions and actions of critical care nurses supports the need

for further understanding of critical care nurses perceptions of legalities as well as ethical perspectives involved with patient confidentiality.

Critical care nurses are not only required to implement the legislation related to health information, but to reconcile application of the law with ethical principles and obligations as they pertain to individual clinical situations. For these reasons, it is imperative to investigate the critical care nurses' views of patient confidentiality and how their view is implemented into their practice. Also important is the critical care nurse's understanding and knowledge of confidentiality legislation and the impact to their patient population and their practice. Elements of practice in critical care units, such as visitation, physical design of the unit and individual relationships among nurses with patients and patients' families also impact nurses' care. Investigation of critical care nurses' perceptions and the impact of these issues on patient confidentiality are necessary to further understanding of critical care nurses' perceptions of patient confidentiality.

Critical care nurses' actions are in the heart of patient confidentiality. With the mass information included in state and federal legislation as well as the impact of ethical principles and codes of ethics, decisions regarding patient confidentiality may be difficult for the bedside practitioner to navigate. Often, decisions are necessary without extended time for evaluation of the nuances of the law and the ethical principles and theories pertinent to each case-specific situation. Exploration of critical care nurses' perceptions of confidentiality can lead to understanding of their thought processes and decision making in situations that involve patient confidentiality and potentially further nursing education and support of nursing practice in critical care settings.

Assumptions

There are several assumptions made about critical care nurses' knowledge and perceptions of confidentiality legislation and their ethical obligations.

1. Critical care nurses have been exposed to some education regarding confidentiality laws, including HIPAA.
2. Critical care nurses have been exposed to some education regarding the ethical principles of confidentiality, autonomy, beneficence and non-maleficence.

CHAPTER 2

REVIEW OF LITERATURE

The purpose of this study was to explore the critical care nurse's perception and knowledge of patient confidentiality. Critical care nurses are a fundamental part of the relationships that health care recipients build throughout their healthcare experiences. Literature, legislation and organizational codes of ethics, all demand that part of that fundamental role include maintenance of confidential health information. Thus research regarding critical care nurses knowledge of confidentiality legislation and ethical duties is warranted. Inquiry into the critical care nurse's perception of patient confidentiality will lead to further understanding of what patient confidentiality is, who it applies to and critical care nurse's perceptions of how patient confidentiality affects their practice and the patient relationship with nurses and other health care providers.

Pertinent literature focused on (a) literary and research support related to health care confidentiality, (b) federal and state legislative support for protection of health information, (c) case law supportive of protection of health information, (d) legislative support for release or breach of protected health information (PHI), (e) case law supportive of release or breach of PHI, and (f) the synthesizing framework for this study, Therapeutic Jurisprudence (TJ).

A comprehensive review of literature was completed using pertinent and key words related to patient confidentiality and the Health Insurance Portability and Accountability Act (HIPAA). Databases included literature from nursing, medical and sociologic fields of study.

Primary focus was given to current literature, published in the latest five years, although classic literature was also incorporated. Specifically, literature and studies were sought that addressed critical care nurses' views of patient confidentiality. After completion of the search, several studies were found that addressed patient confidentiality; one in particular addresses the application of HIPAA in critical care settings (Roberts, 2003). Kowalski et al. (2003) explored the perceptions and experiences of neonatal critical care nurses and parents of neonatal patients' perception of unit visitation policy and unit architectural design and the implications on protection and privacy of health information. Many other literary works were reviewed related to HIPAA and protection of health information. The literature search was then expanded to include general care nurses' perceptions and experiences with patient confidentiality and literature related to the health care consumers' and families' perceptions of patient confidentiality.

Many articles addressed the incorporation, application and outcomes of the legal aspects of PHI. Search for legislation supporting protection of health care information included legal journals, databases, federal and state legislation and case law. The literature search included information related to health care law as well as ethics and protection of health information. Literature incorporating the ethical components of protection of health information was not extensive; however, the literature reviewed was applicable to the purpose of this study, to explore critical care nurses' perceptions and knowledge of patient confidentiality.

Related Literary Support and Research

According to Quallich (2002), protecting confidential health information is one of the most difficult tasks facing healthcare workers today. In a survey distributed by the Wall

Street Journal, Smith (2000) reports that loss of personal privacy was listed as the number one and two concerns by 29% of the respondents. Loss of personal privacy ranked as a higher concern than global warming and terrorism, clearly indicating the community's desire to protect confidential information (Smith, 2000).

This strong desire to protect confidential information begs the question as to what is considered confidential. It is imperative for critical care nurses and other healthcare providers to understand the answer to this, to ensure protection of clients' health information. Many definitions of confidentiality exist for varying fields of healthcare. Paul Cain (1999) refers readers back to their organizational or professional code of ethics and states that generally, confidential information is any personal or private information; information that may be used to identify an individual or information given in the strictest of confidence. Cain found that most healthcare workers view confidentiality as any information obtained in professional practice. With this in mind, this study focuses on the critical care nurse's perception of patient confidentiality.

There have been multiple studies regarding privacy and/or patient family needs in health care. Kowalski et al. (2003) examined parent and nurse perceptions of confidentiality and visitation in an open structure neonatal intensive care unit (NICU). The authors interviewed both nursing staff ($n = 18$) and parents ($n = 16$) of neonates in the NICU. The NICU had an open visitation policy and only limited visitation during rounds, shift change, procedures and emergency situations. Half of the parent participants and 84% of the nurse participants agreed that confidentiality was important to them. More than half of the parents reported discussing the condition and care of their baby with other families in the waiting area. The authors attribute this sharing of information to needs of support and coping among

families. Although some nurses (32%) reported experiencing difficulties when parents were asked to leave the unit during rounds, almost all of parent participants (90%) reporting being unable to hear and/or understand information when they were allowed to stay during medical rounds. Both parents and staff reported inconsistency with application of the policies. This inconsistency was reported as frustrating by both the nursing staff as well as parents. None of the nurses recommended diminishing visitation time and 81% of the parents understood the need for limited visitation during rounds and shift change when confidential information was being shared. The authors deduced the overwhelming concern for confidentiality, the primary purpose of the study, was unfounded as the parents indicated sharing the information about their baby despite policies already in place (Kowalski et al., 2003).

Similar to the NICU study, Rylance (1999) interviewed 300 parents about their experiences with privacy, dignity and confidentiality during their child's inpatient stay in a hospital. Ninety-two percent of participants admitted that they had overheard confidential information about other patients during their stay (Rylance, 1999). This significant confirmation of breaches in confidentiality is a wakeup call to all hospital personnel regarding communication of personally identifiable health information and the need to be cautious when speaking to and about patients.

One key aspect of both these studies is the participant population. Participant parents reported sharing information about their neonates and underage children who had no decisional capacity. In an adult critical care unit, patients normally in control of their own health and health information often experience periods of incoherence that are temporary. If the neonate and pediatric study were generalized to an adult population, when the adult's condition improved, they might object to this sharing of information with strangers.

Several critical attributes of confidentiality are examined in this research: Communication of information, minimum standards, fidelity and consistency as well as prudence, compassion and understanding of confidentiality and privacy. The NICU study is evidence of the understanding and application of policies and procedures that affect confidentiality, held by nursing staff and families of patients in critical care settings

Information sharing is central to the concept of confidentiality. Whether the information being shared is between healthcare providers, providers and patients and families or as in the NICU study, between the families of patients, the need for information is essential. Kirchhoff et al. (2002) state that uncertainty is reduced when family members have access to information and resources. Gelling and Prevost (1999) approached 42 family members of neuroscience critical care patients, 38 nurses and 14 physicians with a questionnaire that contained 30 need statements. Participants were asked to rank the importance of the need using a four-point Likert scale from (1) not important to (4) very important; whether the need was being met (yes, no and sometimes); and who was most appropriate to meet their need (physician, nurse, physical therapist, manager, social worker, friend patient or other). They found that need for information ranked the highest as perceived by relatives ($M = 3.98$), nurses ($M = 3.97$) and doctors ($M = 3.64$). Also, while the need for information was perceived as primary, both nurses and physicians underestimated this need as compared to relatives of patients. The author points out statistical significance ($p = 0.006$) in the fact that a smaller percentage of nurses (53%) than families (83%) and doctors (86%) considered the need for information as most important. When asked who was most preferred to meet the need for information, nurses were ranked the highest to meet this need (52%) for general information and physicians were second in providing specific

information (48%). The difference in physician and nurse perception of who meets the need of information was statistically significant ($p = 0.001$). Given the importance placed on information sharing by these respondents and the expressed desires to receive information from the critical care nurses, it is imperative that we begin to explore the perceptions that critical care nurses have regarding sharing information and patient confidentiality. The authors suggest that healthcare workers in the intensive care unit (ICU) include the family's need for information as an integral part of the plan of care. Gelling and Prevost (1999) suggest that this inclusion in the care will allow for holistic care of the client as well inform the client's family members and perhaps lesson anxiety and stress experienced as a family member of a patient in the ICU.

De Jong and Beatty (2000) asked 84 family members of critically ill patients in a military medical center their perceptions regarding support interventions and how often those interventions were implemented by nursing staff. In this study of family needs, the authors found that families ranked the need for relief of anxiety and information as the most important on a Likert-type scale with five being the highest need ($M = 4.74$). The authors agree with Gelling and Prevost (1999) that having a family member in the ICU is stressful and anxiety producing. De Jong and Beatty suggest that nurses should include the families of their clients in the plan of care to perhaps lesson the anxiety and stress associated with hospitalization.

Slutsman, Kass, McGready, and Wynia (2005) surveyed a population of physician participants. The study, conducted prior to HIPAA enactment, surveyed 933 physicians' perceptions and knowledge of HIPAA yielded that 52% of the physicians were very familiar with their organization's privacy policy and 55% reported being somewhat familiar with

HIPAA (Likert scale of very familiar, somewhat familiar, not very familiar and unfamiliar). Forty-six percent of the physicians strongly disagreed that HIPAA legislation would aid their efforts to protect their patients' confidentiality. Respondents were asked to rate their individual organization based on its privacy policies. Organizations with more privacy regulations in place were seven times more likely than those with fewer policies to better protect the confidentiality of medical records ($p \leq .0001$). These organizations' policies were five times less likely ($p = .0001$) to interfere with physician performance of care. Organizations with paper medical records were twice as likely ($p \leq .01$) to better protect confidentiality and were three times more likely ($p \leq .0001$) to have dissemination of privacy policies (Slutsman et al., 2005).

The authors note that these findings are contradictory. Organizations with more policies and procedures in place to protect patient confidentiality were rated more positively by physician respondents yet almost a majority of respondents strongly agreed that HIPAA legislation would not help further protect confidential health information. The authors attribute this to potential uncertainty of additional gain from the legislation due to previously existing policies. Physician knowledge or beliefs about ethical perspectives of confidentiality and its impact on legislation were not assessed. Perhaps the contradiction is related to physician beliefs that ethical standards and beliefs are enough regulation of confidentiality. Additional studies of physician perceptions of HIPAA legislation as well as ethical duties to confidentiality should be conducted to further provide insight to the effect of legislation on provision and quality of care (Slutsman et al., 2005).

The results of this study demonstrate the dilemma of unfamiliarity and the potential for inconsistency that patients in critical care and their families face. Prior to HIPAA

enactment, physicians were unsure if there would be any gain from stricter confidentiality legislation. Patients and family members of patients in critical care settings may also face uncertainty about the legislation, its purpose and benefit to their circumstance. Health care providers should be familiar with legislative controls, but also with codes of ethics for provision of care and communications with patients and family members.

Internationally, a few research studies related to confidentiality and codes of ethics exist. Of most interest and application to nurses' perceptions of confidentiality is a survey of Israeli nurses in both a community and hospital setting. Hospital nurses (536) and community health nurses (239) responded to a survey of their experiences with ethical dilemmas. Nurses reported experiencing an average of 15 ethical dilemmas within the year prior to the study. Hospital nurses most frequently reported conflict between patient and family needs (74%). Withholding information from the patient at the family's request was also a source of conflict (62%). These ethical dilemmas are frequent in the critical care setting. Community health nurses similarly reported conflict between patient and family needs (69%) and withholding information from patients at the family's request (45%) (Wagner & Ronen, 1996). These issues are ones faced often by critical care nurses.

Confidentiality issues, although not significantly, were more frequently reported by community health nurses. Hospital nurses reported use of the code of ethics (34%) and the patients' declaration of rights (44%) for guidance in resolution of ethical dilemmas. Only 31% of both hospital and community health nurses were familiar with any statement in the Israeli code of ethics for nurses. Most nurses reported their ethical attitudes and beliefs were based on family and personal beliefs (Wagner & Ronen, 1996).

The high incidence of confidentiality-related issues and patient family needs reported in this study demonstrate issues faced by hospital nurses in Israel, but also commonly seen in my own practice and likely that of other critical care nurses in the U.S. The need for examining the scope of understanding and knowledge of legal and ethical obligations regarding confidentiality in Israel is clear, but can be generalized to demonstrate the need for further study in the U.S.

As communicated by the Israeli nurses, Dimond (1999) also recognizes that there are occasionally discrepancies among the relatives' motives and understanding of confidentiality. She states that theoretically, the patient has the right to control all information related to himself and his health, but that in certain circumstances, this self-control is not always possible. Dimond (1999) suggests that in these instances, that medical and nursing personnel turn to the family members of such patients to convey confidential health information. According to Lisseman (2000), in the U.K., disclosing information to the family or next of kin can be difficult as the definition of family and next of kin is obscure when in the context of information giving as opposed to definitions of the same in circumstances of property for example. Lisseman (2000) reminds readers that their primary responsibilities are to the patient, then the family.

An Australian study found that of 235 emergency department patients surveyed, 96 of the respondents overheard conversation involving another patient and 36 felt their private information was overheard by others not involved in their care (Karro et al., 2005). Ten participants stated that they withheld information to health care providers due to lack of privacy and also reported feeling other patients and visitors were able to see personal parts of their body. Twenty-three respondents reported being able to see personal parts of other

patients during their stay in the emergency department. Two hundred and two of the respondents indicated that privacy was important and 10% reported that their privacy needs were not met. Physical environment of the patient locations affected the extent of the breach of privacy and confidentiality. Patients in walled cubicles were less likely to overhear or see other patients inappropriately and were less likely to report breaches of their own privacy and confidentiality. Patients who felt their private information was overheard were more likely to withhold information from health care providers ($p \leq .0001$) (Karro et al., 2005).

This study addresses a large number of critical attributes of confidentiality. Privacy, communication, prudence and discretion, compassion and trust are addressed in this Australian research. The information gleaned from this study is exemplary of dilemmas faced not only by patients in the emergency room, but those faced by patients in critical care units. Both critical care and emergency departments often have similar physical architecture. Both environments are historically noisy, busy and have varying visitation policies. Protection of physical and non-physical privacy and confidentiality are imperative to trusting relationships amongst health care recipients and providers. Prudence and discretion, compassion and respect for autonomy and dignity are critical attributes necessary to promote privacy and confidentiality.

Andershed and Ternstedt (2000) noted their participants associated feelings of trust, openness and sincerity, confirmation, support and connection with information sharing. The authors described participants who reported being well informed and included in patient care as being “involved in the light” (p. 151). The authors interviewed 52 relatives of patients who were diagnosed with cancer and who later died while hospitalized on a surgical unit or hospice unit at a medical center in Sweden. If participants reported a lack of information

sharing among themselves and healthcare workers, despite a desire to know information, these participants were said to be “involved in the dark” (p. 151). Participants who were involved in the dark reported feeling a lack of openness and sincerity, avoidance and exclusion and a disconnection with staff members. These participants also reported a lack of trust among healthcare workers (Andershed & Ternstedt, 2000).

Cochran (1999) discusses the issue of trust and how a lack of trust can be detrimental to the care provided to an individual or family. However, where Andershed and Ternstedt (2000) suggest that sharing of information leads to building of trust and connection to healthcare workers, Cochran (1999) and Lisseman (2000) suggest that divulging or revealing patient information leads to a lack of trust and is an unprofessional breach of respect to the patient. Cochran recognizes the need to involve the family in the care of the client and to keep the family informed, however, she states that the line between including the patient’s family and protecting confidential health information is a fine one at best. The author offers many suggestions in dealing with confidential health matters. Specifically, she reminds readers that as a healthcare professional, an obligation to protect the confidential health information of the client is enabled (Cochran, 1999).

Quallich (2002) agrees with Cochran and Lisseman that protection of health information leads to a feeling of trust between patients and healthcare workers. She states that healthcare professionals must make a conscientious effort to protect confidential health information and resist the urge to share information with well-intentioned family members.

Meier (2002) also recognizes that the trust of the healthcare worker affects patients and family members in seeking healthcare. Meier suggests that fear of breaches in confidentiality may deter some clients from seeking needed care or choose not to share

certain health information that may be pertinent in the correct diagnosis and treatment of medical conditions or preventative options. The author reminds readers that revelation of confidential information may have fatal implications for the client and impede their safety (specifically in cases of domestic abuse) and in order to prevent such detrimental outcomes, informed consent must be obtained prior to the release of any information no matter how seemingly insignificant.

Similar to Andershed and Ternstedt (2000), Trueman (2000) discusses patient confidentiality as encountered in the realm of patients with terminal illness. Trueman specifically addresses collusion of the family members of terminal clients with healthcare workers in delaying or foregoing telling the client about their condition. The author does not support nor denounce the act of collusion, but provides sound arguments for and against collusion using the ethical frameworks of utilitarianism, deontology and rule utilitarianism while considering issues such as autonomy, confidentiality and the best interest of the client. While no finite conclusions are reached, the author states that it is highly probable that nurses and family members may both feel that they are protecting the patient's best interest while still disagreeing upon the decision to collude or not to collude with family members regarding information about the client.

Whetten-Goldstein et al. (2001) conducted three focus groups comprised of an undisclosed number of patients diagnosed with Human Immunodeficiency Virus (HIV) to assess their perceptions of confidentiality. The authors state the majority of the participants viewed confidentiality as important, but that in reality it did not exist in a medical setting. All participants, save two, identified that they had experienced a breach of confidentiality. When asked how perceived breaches occurred, word of mouth and family members were listed as

number one. The authors identified that patients seemed to have a more rigorous definition of a breach of confidentiality than healthcare workers. This information from patients about their perceptions of confidentiality supports information from the studies discussed previously that patients, family members and healthcare workers seem to have differing perceptions about the concept of patient confidentiality, further demonstrating the need to further explore the critical care nurse's perception and knowledge of patient confidentiality.

In a study conducted with patients and their caregivers, Woods, Beaver, and Luker (2000) asked participants ($n = 44$) to comment on their experiences with the palliative services they were receiving. Without prompting or specific questioning, most participants brought the topic of confidentiality to the table. The authors noted that again, differing perceptions of confidentiality between clients, family members and even among healthcare workers exist. Some participants viewed the concept of confidentiality as an obstruction, a harmful barrier and an assertion of healthcare workers' professional authority. The authors conclude that while a breach of confidentiality may be ethically wrong, to deny the strength of the bond among patients and their families or caregivers may be just as wrong. The authors suggest that healthcare professionals establish ground rules from the beginning of interaction with clients and families regarding confidentiality to assist in bridging the gap in the many definitions and perceptions of confidentiality.

Federal Legislative Support for Protection of Health Information

Critical care nurses are legally obligated to protect the health information of their clients. Legal protection of information about health care recipients is supported via federal legislation by HIPAA. One aspect of the act regulates the portability of health insurance coverage of individuals during employment changes, regardless of pre-existing conditions.

Other facets of the privacy rule regulate the access, usage, sharing and storage of PHI. Another purpose of the legislation is to diminish fraud and abuse in the provision of and payment for health care. Protection of health information became a national priority under the George H. W. Bush administration in the 1990s. During the Clinton administration, the Clinton Health Plan was not accepted as legislation, but after revision, HIPAA was enacted as P.L.104-191 in 1996. Final regulations were accepted in 2000 and recorded in the Code of Federal Regulations (C.F.R.) title 45 §§ 160-164. Compliance was required by April 14, 2003. This legislation, administered by the Department of Health and Human Services (DHHS), Office of Civil Rights, provides a legal minimum standard to protect the privacy and confidentiality of health care recipients. HIPAA does not preempt state law when state law is more restrictive about privacy and confidentiality of health information (Erickson, 2005; Erlen, 2004; Flores & Dodier, 2005; Harman, 2005; Kelly et al., 2002; Kuczynski & Gibbs-Wahlberg, 2005; Office for Civil Rights, 2011; Owen, 2000; Roberts, 2003; Preemption of State Laws: General Rules and Exceptions, 2002).

The details of HIPAA legislation are complex and can be difficult to interpret. It is imperative that healthcare workers understand the terminology and application of healthcare privacy legislation. There are key components and definitions which impact healthcare workers specifically. Agents and agencies affected by HIPAA are declared covered entities. HIPAA supports confidentiality through standards of accountability for covered entities with access to PHI including healthcare workers, agencies, organizations (public and private), healthcare clearinghouses, health plans, government agencies, private businesses and essentially any person or organization who has access to PHI (Clark, 2004; Erickson, 2005; Erlen, 2004; Flores & Dodier, 2005; Harman, 2005; Kuczynski & Gibbs-Wahlberg, 2005;

Lucas & Adams, 2004; Office for Civil Rights, 2011; Roberts, 2003; Definitions, 2006; Yang & Kombarakaran, 2006).

Subparts of The Public Welfare General Administrative Requirements (2000), 45 C.F.R. § 160 support protecting confidential information by outlining the general administrative requirements regarding key definitions, preemption of state law, compliance and investigation, civil penalties, and procedures for hearings. Referral is made to U.S. Code (U.S.C.) title 42 § 1320d-6 which requires civil penalty up to \$250,000, but also criminal penalty up to 10 years imprisonment, dependent on the intent and use of the individually identifiable health information (Office for Civil Rights, 2011; Wrongful Disclosure of Individually Identifiable Health Information, 2005). Title 45 § 162 of The Public Welfare Administrative Requirements (2000) addresses institutional and organizational requirements to protect PHI. Subparts D and F address unique identifiers for health care providers and employers, along with requirements for billing, insurance and referrals.

The most discussed and familiar parts of HIPAA to healthcare workers are found in § 164 of the act. In this section, regulations regarding standard requirements for security and privacy are addressed. Implementation and applicability of the regulations are delineated in subpart A. Subpart C is supportive of protection of electronic PHI via administrative, physical and technological requirements, such as data back-up and physical requirements of work stations. Subpart E details the protection of individually identifiable health information, likely the most popular information known about HIPAA legislation. This subpart discusses uses and disclosures of PHI, de-identification (the removal of all identifiable information) of PHI, accountability for disclosure of information and patient rights regarding PHI. Patient rights to notice of privacy practices, request restriction to access of PHI, request access to

and/or copies of the medical record, amend the medical record and request documentation of disclosures of PHI are delineated in this subpart (Notice of Privacy Practices for Protected Health Information, 2002).

North Carolina State Legislative Support for Protection of Health Information

Legislative support for protection of information about health care recipients is also documented by individual state jurisdiction. Much of the North Carolina state legislation is dedicated to protection of health information contained in medical records, both traditional and electronic (Health Care Facilities and Services, 1973; Security of Health Data, 1983). Specific support for protection of information about health care recipients is made in N.C.G.S. Confidentiality of Records (2002) for records of individuals diagnosed with AIDS or any condition that requires reporting. The statute requires that these records are strictly confidential except for required release for situations such as statistical purposes, treatment and care of the patient, protection of the public as ordered by the local health department, or by subpoena or court order. N.C. General Statutes Access to Health Information (2004), Confidentiality of Records (2006) and Confidentiality of Patient Information (1994) have similar wording to federal HIPAA legislation and refer to Public Welfare §§ 160-164 (2000). Both federal and state statutes indicate that medical records are confidential except for purposes of treatment, payment, billing and other health care requirements (Access to Health Information, 2004; Confidentiality of Patient Information, 1994; Confidentiality of Records, 1997, 2002, 2006; Declaration of Patient Rights, 1997; Definitions, 2006; Physical Safeguards, 2000; Uses and Disclosures to Carry out Treatment, Payment, or Health Care Operations, 2002).

Protection of health information about health care recipients excluding the medical record is addressed in the Declaration of Patient Rights (1997). This statute states “case discussion, consultation, examination, and treatment shall remain confidential and shall be conducted discreetly.” N.C. legislation requires that all patients receive notification upon admission of their rights as patients and the patient bill of rights be publicly displayed in all facilities (Notice to Patients, 1983).

In addition to protection of health information, NC legislation supports the protection of communication with health care recipients. The general statute recognizes the need for nurse-patient privilege and indicates that no disclosure of patient-nurse communication should occur, except under direction of a superior or district court judge for purposes of justice (Nurse Privilege, 2004). In 2006, legislation was enacted that waived the physician-patient and nurse-patient privilege in instances of child abuse and disclosure of information related to impaired driving accident cases (Physician-patient & Nurse Privilege Waived in Child Abuse; Disclosure of Information in Impaired Driving Accident Cases, 2006).

N.C. statutes regarding the patient medical record as well as other confidential patient information is described in general terms such as medical records are confidential and not public and treatment, consultation and examinations should be “discreet.” These terms are considerably general and do not explicitly define how medical records and other patient information, as well as the administrative, physical and technological maintenance of confidential patient information should be managed. HIPAA preempts N.C. state law in this instance and therefore, healthcare workers and other covered entities should defer to federal law when in need of support for protection of information about health care recipients. As advocates for their patients, critical care nurses and other health care providers should be

familiar with the statutes in their state and apply the most restrictive legislation regarding medical privacy.

Case Law Support for Protection of Health Information

Case law is often supportive of protection of confidential patient information. Caplan (1995) discusses a case where a 22-year-old Virginia man died after being shot. His organs were donated; three people were recipients of his organs. Each of the recipients tested positive for HIV after their organ transplantation. The source of the transmission was traced to the organ donor. This information, including the donor's name was released to the media. Caplan (1995) concludes that names of organ donors should remain private to encourage support of respect for donors' and their families' privacy and to encourage future donation by others.

A nationally known case involving Terri Schiavo encouraged support for healthcare providers' legal obligation to keep information pertaining to clients confidential. Throughout the trial and appeals by the Schiavo family, multiple interviews to national and local media were given by several involved parties. Carla Anne Sauer, Terri's registered nurse, was among those discussing the case and the details of Terri's condition. She disclosed information via affidavit in court (as required by Florida state legislation) regarding Terri's condition and the behavior of Michael Schiavo, Terri's husband. She then continued her disclosure via local and national media, including Cable News Network (CNN) (a direct violation and breach of confidentiality). The Florida Department of Health, an umbrella department encompassing all Florida health care divisions including the board of nursing, charged her with breach of confidentiality as required by Florida Administrative Code (F.A.C.) (Unprofessional Conduct, 2009). The Department of Health proposed a fine of

\$1700 and revocation of licensure to practice nursing. Carla's attorney has requested an administrative hearing (NewsMax.com Staff, 2006). As of March 23, 2011, Carla Sauer has an active Florida state nursing license without any disciplinary history (Florida Department of Health, 2011).

In *Bouvia v. Superior Court* (1986) plaintiff Bouvia petitioned to have her nasogastric feeding tube removed stating it was her right to request its removal. This case, usually associated with right to die cases, involves fundamental rights of privacy. Ms. Bouvia, a 28-year-old female diagnosed with cerebral palsy since birth and a quadriplegic was bed bound and therefore required significant assistance with self-care including that of feeding. She was deemed mentally competent and had even earned a college degree. Despite her vehement protest against the feeding tube placement, the tube was inserted and force feeding began. She petitioned the court for injunction against the tube. Based on the belief that preservation of life outweighed the right to die, the request was denied. The feeding tube remained. Appeal was made to the California Court of Appeals and judgment in favor of the plaintiff was granted. The Court of Appeals stated the plaintiff had a legal right to die and live her natural life in dignity and peace. Associate Justice Beach commented that dignity is a part of one's fundamental right to privacy (*Bouvia v. Superior Court*, 1986). While this case primarily deals with the right to die, it is exemplary of the court's view of the right to die as part of the fundamental right to privacy and therefore decisions regarding one's health and life are also deemed private.

In Indiana, in case *Doe v. Methodist Hospital* (1997) the complainant filed suit secondary to his belief that his confidentiality was breached. In 1990, Mr. Doe, a postal worker, was injured while at work. He was subsequently taken to the hospital via the

emergency medical service (EMS) whom he notified of his positive HIV status. Mr. Doe's coworker, Logan, inquired about the plaintiff's condition by contacting his spouse, Lizzy Logan, who worked at the hospital where Mr. Doe was receiving treatment. Mrs. Logan viewed the patient's medical record and discovered his HIV status, which she subsequently shared with her husband. Mr. Doe alleged that Mr. Logan shared the information with other coworkers who then shared the information with several others not already privy to the information. On previous occasions, Mr. Doe had spoken of his HIV status to a few close friends and coworkers, but not to his coworkers in general. Mr. Doe sued for invasion of privacy. Summary judgment was granted in favor of the defendant. Opinion of the court was that no violation of Indiana statutes regarding privacy was substantiated; invasion of privacy did not place the patient in false light and the information was contained to a small group and therefore not defined as publicized as defined by Indiana privacy statutes. Mr. Doe appealed the case and the judgment was affirmed, even though the court recognized a breach of confidentiality. The appellate court agreed with the trial court and the judgment affirmed secondary to that the facts that the case did not establish the information as "publicized" as defined by the current statutes. Justice Najam opinioned that the decision should be reversed in support of protecting health care recipients' private information as disclosure of private information, even to one person should be considered publicized (*Doe v. Methodist Hospital*, 1997). This case occurred prior to HIPAA legislation, where the outcome of the case would likely have been significantly different and in favor of the plaintiff.

In *Griswold v. Connecticut* (1965), it was determined that the penumbra of the Bill of Rights allows particular zones of privacy. This right of privacy extended to the marriage bed and the determination of married couples to seek contraception. This case was precedent for

Eisenstadt v. Baird (1972) which determined that it was unconstitutional for any state to deny access to contraceptives to any adult, regardless of marital status. Both of these cases were precedent to one of the most popular cases dealing with the right of privacy, *Roe v. Wade* (1973). The *Roe v. Wade* case, based on precedent set via *Griswold v. Connecticut* and *Eisenstadt v. Baird* legally said that it is within the woman's right of privacy under the due process clause of the fourteenth amendment to seek and obtain an abortion up to a medically determined point of viability. *Roe v. Wade* has been a much debated legal decision due to individual and group ethics, morals, values and beliefs. While these cases, *Griswold*, *Eisenstadt* and *Roe* use the term "privacy," it can be construed that "privacy" and the protection of an individual's health information are synonymous.

Legislative Support for Release or Breach of Protected Health Information

There are often circumstances where critical care nurses may be asked or required to share PHI about their clients. In certain circumstances, HIPAA and state law permit disclosure of information without permission of the individual. In the instance of emergency or incapacity, healthcare workers may use their professional judgment in regards to disclosure of information. HIPAA does not require that every risk of disclosure of PHI be eliminated. Federal legislation does not impugn the incidental disclosure of information as long as reasonable effort and measure was taken to prevent the disclosure and the disclosure was minimally necessary (Affirmative Defenses, 2009; Office for Civil Rights, 2011; Uses and Disclosures of Protected Health Information: General Rules, 2002).

The most widely known reason for disclosure of information is for public interest and benefit. As defined by federal and state legislation, PHI may be released to officials in prevention or control of communicable illness. Release of information is permitted to

individuals who may have been exposed or have contracted a communicable disease. Release of information may be required as directed by the Food and Drug Administration (FDA) as well as to employers in circumstances of work-related injuries or medical situations which require monitoring as governed by the Occupational Safety and Health Administration (OSHA). Disclosure of information is required in instances of abuse, neglect or domestic violence, judicial and administrative proceedings and for law enforcement purposes. Information may be released without consent to funeral directors, coroners and medical examiners as necessary for identification of decedents, examinations and other duties of these professionals. Disclosure of PHI is mandated for essential government functions and for serious threats to the health and safety of others (General Rule and Exceptions, 2002; Office for Civil Rights, 2011; Uses and Disclosures for Which an Authorization or Opportunity to Agree or Object is Not Required, 2002; Uses and Disclosure of Protected Health Information: General Rules, 2002).

Case Law Support for Release or Breach of Protected Health Information

Healthcare legislation is often the result of judicial decisions rendered when the real life experiences of healthcare providers and clients are in conflict. Occasionally, protecting the confidentiality of healthcare recipients may be in conflict with the concern for others. In a 1976 landmark case, *Tarasoff v. Regents of University of California* the court decided that in an effort to prevent significant or mortal harm to another, disclosure of health or confidential information may be released in circumstance of foreseeable harm to self or others. The facts of the Tarasoff case demonstrated that Dr. Moore, a psychologist at the Cowell Memorial Hospital at the University of California and therapist of Prosenjit Poddar did indeed warn the campus police of Poddar's threat to kill Tatiana Tarasoff. The campus police detained

Poddar, deemed him rational and he was subsequently released. Dr. Moore approached his superior and was instructed to take no further action. There was no warning given to Tatiana Tarasoff. Two months after the fact, in October 1969, Poddar killed Tarasoff. The Tarasoff family brought suit stating but for the negligent actions of Dr. Moore, his superior and the hospital, Tatiana wouldn't have been harmed. The court ruled in favor of the plaintiffs, recognizing the obligation to protect a third innocent party outweighs the duty of confidentiality (Beauchamp & Childress, 2001; Burkhardt & Nathaniel, 2008; Knopp & Satterlee, 1999; *Tarasoff v. Regents of University of California*, 1976).

The court concluded that when therapists determine their patient presents a serious threat of violence to others, the therapist is obligated to protect the intended victim, to warn the proper authorities and to make reasonably necessary efforts, pertinent to the situation, to prevent harm to innocent third parties. The court recognized the inability to predict the behavior of others, and deemed that health care providers and therapist should exercise their own judgment without liability in regards to breach of confidentiality, in an effort to prevent harm. Given this landmark decision, the concept of foreseeability has become imperative in consideration in respect of confidentiality and the duty to warn (Burkhardt & Nathaniel, 2008; *Tarasoff v. Regents of University of California*, 1976).

N.C. legislation does not require a duty to warn, but states that health care providers “may” disclose confidential information if there is a perceived imminent danger to the patient or others (Outpatient Commitment; Examination and Treatment Pending Hearing, 2004). Virginia legislation, as of 2005, requires a duty to warn in cases of imminent or immediate threat to others. The recent shooting at Virginia Tech has brought debate about the duty to warn and confidentiality of mental health records (Mental Health Service Providers; Duty to

Protect Third Parties; Immunity, 2005). It is important to note that not all states recognize the duty to warn.

In another case regarding duty to warn, *Safer v. Pack* (1996), the adult daughter of a deceased patient brought suit against the physician who treated her father. Ms. Safer, 10 years old at the time of her father's death, alleged violation of duty in that Dr. Pack had a duty to warn her of her father's diagnosis with a hereditary disease that eventually caused his death. Summary judgment was granted stating that physicians have no duty to warn the child of a patient about genetic risk because the harm to the child is already present. The court held that the duty to warn and breach of confidentiality applies to threats that are imminent and not applicable in this case, as the parent neither threatened nor intended harm to the child (Furrow et al., 2001). While this case is supportive of protecting the information of health care recipients, it further demonstrates the need for case-by-case analysis for support or opposition to protecting information about health care recipients.

Synthesizing Framework

Lisseman (2000) notes that there is limited research on patient confidentiality in the critical care setting. Given this limitation, Lisseman advocates that nurses approach the concept of confidentiality using ethical principles of autonomy, beneficence, maleficence, truth telling and justice as a framework. He recommends that nurses assess each circumstance and act based on the outcomes of analysis using deontological principles (Lisseman, 2000). While the principles of deontology may be at the root of decisions made in the critical care unit regarding sharing of PHI, using this theoretical model allows exploration and insight based solely on ethics, ignorant of the impact of the law.

The ethic of care theory is important to the understanding of nurses' perceptions of patient confidentiality as it places value on "intimate personal relationships, sympathy, compassion, fidelity, discernment and love," all of which are critical attributes of confidentiality (Beauchamp & Childress, 2001, p. 369). The ethic of care proposes that attention to the needs of others and desire to help or act on behalf of others is morally desirable as opposed to enforcement of Kantian principles or rights. The ethic of care focuses on relationships that involve critical attributes of confidentiality, including prudence, trust, fidelity and compassion. There are two key components of the Ethic of Care: mutual interdependence and emotional responsiveness. Mutual interdependence suggests that caring and empathy are required for desirable moral relatedness based on others' needs and not solely on rights. Emotional responsiveness encourages emotional understanding and attention to the needs of others. Actions based on emotion are more morally appropriate or relevant than those actions in adherence to obligations without consideration of the needs of others. The ethic of care theory gives nurses latitude in situations involving confidentiality. Application of the principles of the ethic of care allows nurses to act on the needs of patients or their representatives, without strict obligation to other principles or rights. The theory does not convey absolutes that nurses should not ever uphold principles or rights, but encourages moral action based on care, empathy and understanding of patient needs as opposed to strict adherence to policies and codes. The Ethic of Care incorporates the nurses' perceptions of patient needs and desires in moral actions (Beauchamp & Childress, 2001) but like deontology does not include the impact the law has on the well-being of patients.

One theory that encompasses the ethic of care and considers deontological principles is TJ (Schma, 2000; Kjervik, 2002, 2005). As a theoretical framework, TJ allows the

researcher to provide analysis using deontology as well as care-based ethics but also to consider the impact that the law has on the emotional, psychological and physical well-being of patients (Schma, 2000; Kjervik, 2002, 2005; Wexler & Winick, 1992; Winick, 1996/1997; Winick & Wexler, 2003).

By providing a new lens through which to examine law, therapeutic jurisprudence promises to produce new insights and a newly invigorated interdisciplinary approach to law that will enrich legal policy analysis and improve law's functioning and its ability to increase the well-being of our society. (Winick, 1996, p. 668/1997, p. 206)

Originally introduced in 1987 by Wexler and Winick, this framework for analysis was first intended to critically examine the effects of mental health law on clients within the realm of psychiatry (Madden & Wayne, 2003; Roberson, 2007; Roberson & Kjervik, 2008; Schma, Kjervik, Petrucci, & Scott, 2005; Wexler, 1991b; Wexler & Winick, 1992; Winick, 1996/1997; Winick & Wexler, 2003). The primary goal of TJ is to assess for and optimize therapeutic effects of rule or law and to minimize negative or anti-therapeutic effects (Finkelman & Grisso, 1996; Hutchinson, 2002; Kjervik, 2002; Madden & Wayne, 2003; Schma et al., 2005; Roberson, 2007; Wexler, 1991b; Wexler & Winick, 1992; Winick, 1997; Winick & Wexler, 2003).

TJ can be divided into four areas. The first of which is the role of the law on a field of inquiry. The other areas of TJ inquiry include the therapeutic aspects of legal rules, procedures and the therapeutic features of judicial and legislative law (Wexler, 1991a; Winick, 1996/1997). Concepts of the theory include the *actors* within relationships affected by the law (Roberson, 2007; Roberson & Kjervik, 2008; Wexler & Winick, 1992; Winick, 1996/1997; Winick & Wexler, 2003). In this study, the actors included critical care nurses, their patients and visitors as these individuals and groups are affected by the outcomes of confidentiality laws (both state and federal) and policy. These confidentiality laws and

policies were defined as *rules* within the framework of TJ and were enforced by the actors.

Another concept of TJ is *consequentialism*. Consequences are defined as the outcomes or rights of individuals or groups as a result of the rules. *Outcomes* of rules are considered either *therapeutic* or *anti-therapeutic* (Kjervik, 2002; Roberson, 2007; Wexler & Winick, 1992; Winick, 1996/1997; Winick & Wexler, 2003). These concepts are loosely defined.

Therapeutic outcomes are generally conceived as positive in nature and enhancing of the health and well-being of the actors. In opposition, anti-therapeutic outcomes are considered negative or diminutive of the well-being of the actors (Kjervik, 2002; Roberson, 2007; Roberson & Kjervik, 2008; Wexler & Winick, 1991a, 1992; Winick, 1996/1997; Winick & Wexler, 2003). Therapeutic outcome are the intended outcomes of rules and anti-therapeutic outcomes are the unanticipated or negative results (Roberson, 2007; Wexler & Winick, 1992; Winick, 1996/1997; Winick & Wexler, 2003). For the purposes of this study, the concepts of TJ are well suited as the goal is to understand how the rules are perceived by the actors and how the actors perceive the outcomes of these interactions (therapeutic or anti-therapeutic).

TJ has been applied to the legal rule duty to warn, brought about by the 1976 case *Tarasoff v. Regents of University of California*. Duty to warn legislation came about as a result of a patient disclosing to his therapist his intentions to harm a third party. Duty to warn legislation allows therapists to warn potential victims of threats verbalized by the patient. Some analyst using a TJ lens suggest duty to warn may be anti-therapeutic due to the breach of confidentiality required to warn a third party, outside the therapist/patient relationship. Wexler (1990, 1991b, 1996) comments this breach may lead to withholding of information necessary for treatment due to a lack of trust in the therapist/patient relationship. In opposition, a TJ inquiry might yield that duty to warn legislation is therapeutic as victims of

these threats often include family members. He suggests inclusion of these individuals in therapy sessions (couple or conjoint) supports therapeutic effects of duty to warn legislation (Wexler, 1990, 1991b, 1996).

This framework is empirical and interdisciplinary (Madden & Wayne, 2003; Kjervik, 2002, 2005; Roberson, 2007; Wexler, 1999; Wexler & Winick, 1991b, 1992; Winick, 1996/1997; Winick & Wexler, 2003). Although Finkelman and Grisso (1996) argue that while TJ can be empirical, it has been largely applied theoretically and academic in nature. TJ was initially a legal theoretical approach to critique of mental health legislation, but has been expanded to include other areas of law such as family law, tort law, disability and probate law (Madden & Wayne, 2003). Other areas of legislation examined using TJ include smoking, abortion, physician assisted suicide and malpractice and welfare policy (Kjervik, 2003/2005; Schma et al., 2005) as well as other disciplines affected by law such as social work and medicine (Hutchinson, 2002; Kjervik, 2003/2005; Madden & Wayne, 2003; Roberson, 2007; Roberson & Kjervik, 2008; Schma et al., 2005, Wexler & Winick, 1991b, 1992; Winick, 1996/1997; Winick & Wexler, 2003).

Research guided by TJ outside the realm of law is limited (Wexler & Winick, 1991b). Roberson (2007) used TJ in his nursing research although maintained the realm of psychiatry in his research involving adolescent mental health patients. The movement of TJ into the profession of nursing is largely supported by Kjervik (1999, 2002, 2003/2005; Schma et al., 2005). TJ as a theoretical framework is a good fit for nursing because nursing as a profession and nurses as healthcare professionals are legally regulated. Nurses are required to be registered or licensed. Nursing practice is regulated by the Board of Nursing within the limits of the Nurse Practice Act. Nurses practice their art within legally defined and regulated

environments (e.g. hospitals, nursing homes, medical offices) who in large part receive state and federal funding (Kjervik, 2002). Given the large amount of interaction between the law and nursing, TJ provides an excellent framework for analysis of these interactions (Kjervik, 1999, 2002, 2003/2005). Kjervik (2003/2005) supports the incorporation of TJ into nursing research to help nurses better understand how the law affects the health of their clients and the care that they provide for them. She asserts that given better understanding of the law, nurses can then better advocate for their clients in policy making and research and thus be better served by the law.

According to Wexler (1999), TJ encourages researchers and scholars to ask questions of the law. Critiquing the law in this manner narrows the field of inquiry and may lead to new questions that might not otherwise be addressed (Wexler, 1999). TJ was a good fit for this study because it encouraged the question, “What impact do the rules (confidentiality law, state and federal) have on the perceptions and knowledge of the actors (critical care nurses)?” which was the primary purpose of the study. Using TJ as the framework for this study assisted in analyzing the impact, therapeutic or anti-therapeutic, of the rules (confidentiality law, state and federal) on relationships between critical care nurses, their patients and families. According to Winick (1996/1997), it was important to clarify the actors’ definition of therapeutic. Did the interaction between the rules and critical care nursing produce the intended therapeutic effect or did it lead to diminished or anti-therapeutic outcomes? Finally, TJ was a good fit for this research because it provided a framework for analysis of outcomes and led to reassessment of the rules (Kjervik, 2003/2005; Madden & Wayne, 2003; Wexler, 1999).

While TJ was a good fit for this research, it is not without limitations. TJ is a legal theory that has limited application thus far in the field of nursing. Roberson (2007) applied TJ to nursing research, but maintained his research in the realm of psychiatric nursing. Because of its limited application outside of law and very limited application within the profession of nursing, it may be easily discredited in its uses as an analytic tool. The variables or concepts of the theory are not clearly delineated. Specifically, the terms therapeutic and anti-therapeutic are broad and nonspecific in description (Finkelman & Grisso, 1996). According to Winick (1996/1997) narrowly defining the concepts would limit scholastic freedom and intuitive exploration of the concepts. Winick advocates that given this freedom, researchers must clearly delineate the definition of therapeutic as it applies to their research and be true to this definition throughout their analysis. The use of TJ in empirical research is limited. Most uses of TJ as an analytic tool have been academic and non-empiric (Finkelman & Grisso, 1996).

This qualitative research aims to clarify the concepts of TJ as they relate to patient confidentiality, HIPAA and critical care nursing. Specifically, the purpose of this study was to explore the critical care nurse's perception and knowledge of patient confidentiality before and after HIPAA legislation and to explore their perceptions of its therapeutic or anti-therapeutic effects. Due to these purposes TJ was an appropriate conceptual framework for this research.

Research Questions

To answer the research question, "What are critical care nurses' perceptions of patient confidentiality?" the researcher answered the following questions:

1. What knowledge of legislation and ethics do critical care nurses have related to confidentiality?
2. What observations do critical care nurses have regarding patient confidentiality and its application in their work environment?
3. How do critical care nurses describe their roles regarding confidentiality in the ICU?

Impact of this Study

If patient confidentiality can be viewed through the lens of the critical care nurse and the framework of TJ, the perception or values that critical care nurse express regarding patient confidentiality may yield insight regarding what information this population of nurses values as PHI and what information they communicate with patient's family members and others who visit critically ill patients in the ICU. Adjustments may be made in decision making in the critical care unit regarding the protection of health information. Re-examination of health care policy at all levels may be better operationalized for those nurses in the critical care field of practice.

CHAPTER 3

METHODOLOGY

Purpose and Problem Statement

Patient confidentiality is a major concern for consumers of health care (Smith, 2000) thus maintaining the privacy of health information should be a primary concern for nurses in all fields of practice. Critical care nurses may experience more difficulty with protection of privacy due to the condition of critically ill patients. Often, critical care patients are unable to speak for themselves to identify what they consider confidential information and with whom information should and should not be shared. It then becomes the responsibility of the critical care nurse to advocate for the patient during their critical illness. Exploring the critical care nurse's perception and knowledge, their interpretations and applications of patient confidentiality is warranted for insight into the roles of critical care nurses regarding confidentiality in the intensive care unit (ICU).

The purpose of this study was to examine the research question: "What is the critical care nurse's perception and knowledge of patient confidentiality?" Based on gaps in current literature related to confidentiality and critical care nursing and recent enactment of confidentiality legislation, three research questions were posed:

1. What knowledge of legislation and ethics do critical care nurses have related to confidentiality?

2. What observations do critical care nurses have regarding patient confidentiality and its application in their work environment?
3. How do critical care nurses describe their roles regarding confidentiality in the ICU?

Research Design

In order to answer the research questions a naturalistic, qualitative design was chosen. Qualitative research design allows participants to freely express their perceptions, opinions and lived experiences and therefore allows more thorough and rich, individualized collection of data and exploration of the research question (Brink & Wood, 1998; Hoepfl, 1997; Key, 1997; Marshall, 1996; Neill, 2007; Polit & Hungler, 1997). A naturalistic paradigm allows free exploration of real world, human perceptions, social and organizational realities without superimposed measurement procedures and pre-conceived views of the researcher. This post-positivist research tradition allows thick description of the concepts and encourages inductive interpretation directly from the data (Lincoln & Guba, 1985). Following a naturalistic inquiry tradition, this study sought descriptive and personal information about what, how and why individuals perceive, experience or behave related to the concept of patient confidentiality.

Participants

Kuzel (1999) recommends sample sizes of 5-20 participants for qualitative research. Consistent with their recommendations and normative qualitative research, the sample size was small. Participants included 12 critical care nurses in active practice in a critical care setting. Participants were at least 25 years of age, able to speak English and able to communicate with the researcher for the length of time necessary to adequately convey their ideas and thoughts. Initial participants were recruited by flyers (Appendix A) posted in

critical care units, word of mouth and referral from critical care nurses known to the researcher. Initial participants contacted the researcher face to face or by telephone and were read a scripted statement regarding the study.

I am interviewing critical care nurses in order to identify their perceptions and knowledge of confidentiality law and ethics. Participation in this research study includes partaking in a face-to-face interview that will last approximately one hour and one brief follow up telephone interview. I will be sharing the information that I collect with my faculty committee, but your name and identity will be kept completely confidential. Would you like to schedule an interview to participate in this research study?

Additional participants were recruited by snowballing (referral from one participant that leads to recruitment of another participant and another until the quota of participants or redundancy of data is achieved) (Brink & Wood, 1998; Hoepfl, 1997; Marshall, 1996; Miles & Huberman, 1994; Polit & Hungler, 1997). Sampling continued until redundancy of data occurred and no additional participants contacted the researcher. No exclusion criterion based on race, gender, education, or religion was used in this study. However, for the purposes of this study, critical care did not include emergency or post anesthesia care nurses due to their varying interaction with family members and visitors. Critical care nurses with less than six years experience as a critical care nurse were excluded to ensure the sample was comprised of nurses with enough clinical experience to recall confidentiality before and after HIPAA enactment in 2003.

Pertinent demographic data were obtained using a demographic data form (Appendix B) to gather information such as race, gender, age and length of time as a critical care nurse. The 12 participants were female, Caucasian ($n = 11$) and self-described Greek-Caucasian ($n = 1$) with a mean age of 49 years (range 34-60). Participants had a mean of 21 years' experience as a registered nurse (range 6-38) and a mean of 18 years as a critical care nurse

(range 2-28). Table 1 provides demographic data displayed for each participant as the individualized information may yield insight into the responses of individual participants. In this study of patient confidentiality in adult critical care units, it is important to describe the participant sample as no other known research has focused on patient confidentiality, specifically that of critical care nurses, and their perceptions of patient confidentiality.

Setting

Initial interviews were conducted in locations selected by the participants; all were in central regions of North Carolina. Locations of the face-to-face interviews allowed for respect of confidentiality as well as participant comfort and were chosen at locations most convenient for the participant namely, private offices and private, out-of-the-way areas in book stores, coffee shops and restaurants.

Protection of Human Subjects

This study was granted expedited approval by the University of North Carolina at Chapel Hill (UNC-CH) Public Health and Nursing Institutional Review Board (IRB) (see Appendix C). Informed consent was obtained from participants and documented using the UNC-CH Consent to Participate in a Research Study, Adult Subjects Biomedical Form (see Appendix D). Participants retained the right to terminate the interviews at their discretion; however, no participants declined or terminated participation. Participants were assigned pseudonyms to protect their confidentiality. Other identifying and contact data were destroyed after completion of the face-to-face and telephone interviews.

Procedure

After informed consent was obtained, data were gathered via audio-recorded, conversational, semi-structured interviews conducted by the researcher.

Table 1***Participant Demographics***

Demographic	Anne	Beth	Charlotte	Donna	Evelyn	Frances	Gail	Hannah	Irene	Janelle	Kristen	Lilly
Marital Status	D	M	M	M	M	M	M	M	M	M	M	M
Age	56	44	53	49	53	43	34	40	39	57	60	55
Ethnicity	C	C	C	C	C	C	C	C	GC	C	C	C
Level of Education	DN	BSN	BSN	BSN	BSN	ADN	BSN	BSN	BSN	BSN	BSN	AND
Employment Status	FT	R	FT	FT	FT	FT	FT	FT	FT	PT	PT	FT
Shift Assignment	7p-7a	7a-7p	7a-7p	7a-3p	3p-11p	7p-7a	7p-7a	7a-7p	7a-7p	7a-3p	7a-3p	WEO 7a-7p
Type of Facility	CH	CH	CH	CH	TH	CH	TH	TH	TH	CH	TH & CH	TH
Years' Experience	18	22	32	15	27	6	9	7	13	35	38	30
Years' Experience in Critical Care	17	20	25	15	22	6	4	2	13	26	38	29

Note: D-Divorced; M-Married
C-Caucasian; GC-Greek Caucasian;
DN-Diploma Nurse; BSN-Bachelor of Science, Nursing; ADN-Associate Degree, Nursing
R-Relief; FT-Fulltime; PT-Part-time; WEO-Weekend Option; CH-Community Hospital; TH-Teaching Hospital

Interviews were recorded using a digital voice recorder. Responses to pre-determined, open-ended questions guided the interview (see Appendix E); although participants were encouraged to also discuss topics they felt relevant to the research. Questions were added as the interview progressed and responses warranted further development and exploration of the topic.

Interviews lasted approximately one hour and allowed adequate time for the participants to convey any and all information they felt relevant to the purpose of this study. Each initial interview was followed by a telephone interview conducted one week after the initial interview to allow participants the opportunity to add or clarify further information and for the researcher to further explore questions as necessary. Telephone calls lasted less than 15 minutes and were not recorded.

Data Management and Analysis

Data analysis began after the first interview and continued throughout data collection. Audio recordings and field notes were transcribed verbatim into encrypted electronic word documents and stored on a compact disk by a third party who signed a confidentiality agreement (see Appendix F). Encrypted transcripts and field notes were then downloaded to a password protected computer and a USB mass storage device. The compact disks were subsequently destroyed. Upon transcription of the interviews and field notes, the audio recordings were deleted and the printed transcripts and USB device were stored in a loose leaf binder placed in a locked drawer which will remain in the possession of the researcher for a period no longer than five years.

Data were analyzed using conventional content analysis (inductive category development). This process allowed a systematic approach to reduce the data into categories

through coding, paraphrasing and summation of the data (Bloomberg & Volpe, 2008; Grbich, 2007; Lincoln & Guba, 1985). This process allowed the researcher to immerse herself in the data and to extrapolate categories and themes from the data, rather than from preconceived concepts and theoretical principles (Lincoln & Guba, 1985). The benefit of this type of analysis was categorical production derived directly from the data and the participants (Grbich, 2007; Hsieh & Shannon, 2005; Lincoln & Guba, 1985; Mayring, 2001; Ryan & Bernard, 2000; Spannagel, Glaser-Zikuda, & Schroeder, 2005).

Approach to the data included searching for participant responses, first with-in case then across-cases related to the research questions. The transcripts were read as a whole, case-by-case, to gather an overall impression of the data. After reading the transcripts and becoming more familiar with the participant's responses, the data were coded using keywords from the language of the participants. The data were then paraphrased, to avoid 'word overload' (Huberman & Miles, 1994) and placed into categories. Particularly striking participant quotes were also included and helped establish transferability. Consistent with naturalistic inquiry and inductive content analysis, codes and categories developed as analysis progressed. These data were placed into individual case data folders and matrix tables to allow with-in case analysis. Table 2 is an example of a with-in case data matrix display table. Finally data were placed into a comprehensive category folder and matrix table that included all participant data (cross-case). Table 3 is an example of a cross-case data matrix comparison table of responses to Vignette 1. This management of data allowed definition of participant responses, within case and across cases (Bloomberg & Volpe, 2008; Creswell, 2007; Grbich, 2007; Lincoln & Guba, 1985).

Table 2

With-in Case Data Matrix Display

Question	Response	Summary
Definition/Perception of Concept	Privacy with parameters; privacy of records, conversations and anything physical. “It bothers me when people stand up in church and give someone's medical diagnosis in front of everyone and you don't always know that the person has said that was ok.”	Talks mostly about privacy as opposed to confidentiality. Uses the terms interchangeably. Really connects her personal experiences as a patient as well as a visitor/caregiver and beliefs with her implementation and application of confidentiality to her practice. Associates her perceptions and impact to her practice through multiple "stories". Talks about HIPAA as therapeutic as a "frustrating" but positive in providing a visible back up of hospital policy r/t confidentiality. Is unaware of NC legislation but accurately describe the BONs role r/t confidentiality and its deference to HIPAA. Does not mention the nurse practice act, ethical principles of deontology or theory. Refers to “the golden rule”—ethical reciprocity. Really identifies confidentiality of information with AIDS patients and her role in "ministering" to them. Became very emotional in her discussion of these situations. Integrates maintaining her patient’s confidentiality with who she is as a person.
Most Important Features	The most important to me...is just absolute pure common courtesy. Extend to other people what you would want yourself.	
Expected CCRN Roles	I feel like my patient’s need my protection . I need to be protective to people in general. We are caretakers , we are gatekeepers . “We are the standards ” “We have to monitor ourselves, other people.” Advocate. Educator. Counselor. Minister. Peer monitoring.	
Expected RN Roles	to make others aware of surroundings (curtains in rooms, employee health window)	
Desired Roles	None	
Knowledge of Hospital policy r/t confidentiality	Did not specify policies or rules--began discussing the impact of fed legislation. Spoke of how unit/institution policies “come and go” such as “immediate family only and code words	

Note: Colored text indicates preliminary category development.

Table 3

Across Case Data Matrix Display for Responses to Vignette #1

Anne	Beth	Charlotte	Donna	Evelyn	Frances
“This is one of those iffy, iffy situations where if there are gonna be violations, they probably are.”	First off explain privacy regulations.	I would try to get information from the patient's g/f. (Recruit her to help contact or get contact info for the family).	There would be no question, I would say "I'm sorry, that patient is not here."	I'm really glad to see you. Is there anything you can tell me? If you are his significant other...how can we get in touch with them?	I would ask right away does he have family members. We need a next of kin before we can give you any information.
Ooh, hmm	I would give her a minimal amount of general information.	I think someone has got to give her some information. Maybe not as specific as maybe we would with someone else, but I think we, somebody would.	There has been nothing found on him that ties him and there is no way to prove that she was the live in g/f and she would get nothing.	Get the sheriff's department or someone else trying to chase down his actual address or way to get in touch with his family	I'd call the supervisor and let them handle it. It sounds fishy to me.
Visitors sometimes lie: they never say live in girlfriend, they always identify themselves as fiancé. But that makes no difference to us, but they think it does.	You are not even supposed to verify whether the patient is a patient in the unit or not.	I wouldn't identify each of his injuries because usually that kind of information would come from the physician.	She would be told to leave.	At his point, she is his significant person 'cause there is no one else, so probably yes [I would give information].	I would say not pertinent information, not specific information but I'd say it was ok, whether he was doing ok and we're admitting him to the ICU. He's still unconscious we need next of kin information. She legally has no access to anything and explain that to her.

Note: Colors represent preliminary category development.

Trustworthiness

Lincoln and Guba (1985) specify that in naturalistic qualitative research, reliability and validity are replaced by values of credibility, transferability, dependability and confirmability. Prolonged engagement with the data by listening to the audio recorded interviews and reading the transcripts for clarity and accuracy optimized credibility of the findings. Prolonged and in-depth engagement with the data also occurred through intensive content data analysis and matrix display of the findings. Initial interview transcripts, preliminary analysis and findings were shared with members of the researcher's peers and committee chair (peer debriefing) to ensure that the findings were derived from the data. Inclusion of raw data in the analysis confirmed the findings reflected the data. A brief summary of the findings from each individual interview was shared with the individual participant to ensure the findings captured the essence of the participant's responses (member checks). A clear and concise audit trail through the use of field notes, code books and researcher summaries supported this process, thus enhancing dependability and confirmability. Thick, rich description of the data and the use of participant quotes in the write up enhanced the transferability of the findings (Lincoln & Guba, 1985).

CHAPTER 4

FINDINGS

The purpose of this study was to explore critical care nurses' perceptions and knowledge of patient confidentiality in the critical care setting. A naturalistic qualitative approach using open-ended questions was used to elicit critical care nurses' perceptions and knowledge of patient confidentiality. Initial participants were recruited by flyer and word of mouth. Additional participants were recruited by snowballing until saturation of data was achieved and no further potential participants contacted the researcher. Twelve participants responded and agreed to participate in the study. The 12 respondents were asked what knowledge of legislation and ethics critical care nurses have related to confidentiality. Specifically, nurses were asked to describe their (a) general knowledge of confidentiality legislation, (b) specific knowledge of North Carolina confidentiality legislation, (c) the involvement of the N.C. Board of Nursing (BON) in relation to patient confidentiality and (d) their specific institution's policies and available resources regarding patient confidentiality. Nurses were also asked to describe their knowledge of ethical obligations related to confidentiality.

Participants were asked what observations each had regarding patient confidentiality and its application in their work environment. To assess their observations, critical care nurses were asked to relate experiences that demonstrated the impact and implementation of the Health Insurance Portability and Accountability Act (HIPAA) and hospital policy in the

critical care setting. They were asked to tell stories of their practice before and after HIPAA enactment and of a time when they felt confidentiality obligations were breached.

To assess critical care nurses' description of their roles regarding confidentiality in the intensive care unit (ICU), the nurses were asked to describe (a) their own actual and expected roles and those of other critical care nurses, (b) their knowledge and perceptions of actual and expected roles of other nurses in other types of acute care units and (c) any further roles they desired to play in relation to patient confidentiality.

In addition to the specific questions and discussion related to the research questions, nurses were also given two vignettes that sought their response to clinical situations in an effort to gain insight about their knowledge and interpretation of confidentiality legislation and subsequently, application to their individual practice. The use of participant quotes is provided in bold italic quotation marks and names of participants have been changed to ensure participant confidentiality. Findings are organized relative to the research questions.

Research Question 1: What Knowledge of Legislation and Ethics Do Critical Care Nurses Have Related to Confidentiality?

Knowledge of Confidentiality Legislation

Nurses are knowledgeable. The overriding theme indicated that they are knowledgeable about confidentiality legislation. All of the participants noted that health information was *“protected”* or *“private.”* Others had similar statements to Lilly who commented that *“all patient information is protected from anyone that’s not directly involved in that patient’s care.”* Evelyn’s description of confidentiality law was more specific. She stated,

Again, we are responsible not to divulge patient information to anyone that is not authorized by the patient. Again, in practice, sometimes the patient cannot authorize anybody and we have to go to the next of kin, to the best we can find.

Half ($n = 6$) of the participants further specified that confidentiality legislation excluded anyone who was not directly involved in the patient's care from receiving confidential information. Janelle commented, *"That [patient confidentiality] means that we're not sharing information about that patient with other people that don't need to know that information if they're not involved in helping that person get well."*

HIPAA—don't say anything, don't talk. When asked to identify confidentiality legislation, all ($n = 12$) of the nurses referred to HIPAA. Hannah responded, *"Well, you know, HIPAA—that's probably the biggest one. HIPAA—don't say anything, don't talk."*

All but Kristen were familiar with the application of HIPAA as federal legislation and its application nationwide; she stated,

I don't think I know anything but HIPAA. It probably comes from somebody outside the hospital that's told the hospital we have to enforce it. Whether it's federal law or state law I don't know where it comes from originally.

Charlotte further defined that HIPAA applied to physician offices and insurance companies, sharing of information over the telephone and

in general, patients have to give permission for someone else to get information about their medical condition or their position. I know that physician's offices can't, they have, every visit you make, you sign saying that they can give information to insurance companies. It impacts whenever they are calling with lab results back to you. They have to have permission whether they can leave a message on your answering machines.

Donna commented that verbal communication is protected. She further defined that health care workers should be mindful of their location when information is being shared.

I can be behind other people from the facility, in the cafeteria and they will be talking about something that I wouldn't care to discuss and I can see family members standing there looking at each other, frowning and shaking their heads, I

can see that. So, every time I see that, I think to myself – Don't do that, don't do that.

Hannah indicated specific knowledge of HIPAA in her discussion of incidental breach (Uses and Disclosures of Protected Health Information: General Rules, 2002) when visitors walk past nurses during shift report. She stated, ***“It's a breach. It's a breach but I guess an understandable breach in that you were doing what you were supposed to do appropriately; however the information still got out.”*** All ($n = 12$) of the participants indicated knowledge that there were individual and institutional penalties related to breach of confidentiality.

Nurses know who to talk to. Half ($n = 6$) of the participants demonstrated familiarity with the concept of *“in loco parentis”* (Latin for “in the place of a parent”) in their discussions of sharing information about patients who are unable to make autonomous decisions. Hannah and Charlotte specifically discussed the role of a health care power of attorney (HCPOA). Charlotte commented,

Oh yes, it [HCPOA] makes it much easier in my case, in my view. Because then this person, who is now not able to speak for themselves, at some point gave this some thought and said ‘if I am not able to speak for myself, if I'm not, it's okay for, I want this person to be a spokesperson for me.’

Hannah noted that HCPOA supersedes next of kin and commented in the absence of a HCPOA information could be shared with next of kin; ***“It would be either a spouse or the eldest child that is of age and you go to the mother, father, parent and then you just continue to the next of kin unless they have a power of attorney.”*** Federal legislation requires persons acting as personal representatives or in loco parentis be treated as the individual (Uses and Disclosures of Protected Health Information: General Rules, 2002).

There is no known legislation in N.C. that identifies with whom and the order in which confidential health information should be shared.

In North Carolina, minors who become pregnant and certain others may petition for emancipation. According to the North Carolina General Statutes (N.C.G.S.) § 7B-35 pregnancy does not automatically ensure emancipation unless the minor is legally married (Emancipation, 1998). Lilly commented of her experience,

Sometimes we get teenagers but generally if they've had a baby, they are responsible for themselves. Sometimes their mother might try to take over and I probably would feel that way too as a mother; this is a minor I'm responsible for and I deserve to have that information or say in what's going on.

When asked how she handles those situations, Lilly replied, *“Usually, I contact the supervisor or someone who knows specifically how that relationship works in terms of when the patient is kind of emancipated from their parents.”* No other participants reported caring for minors, others who are emancipated or under legal guardianship.

Nurses know what to share. Participants were quick to identify information that is and is not confidential (see Table 4). All of the participants identified that they could share “general” information. All participants included the patient’s condition as part of general information. Beth described general information to *“include the patient is stable, we are monitoring the patient.”* Donna said she would reply, *“They’re resting comfortably. They are getting better. They are holding their own; very general comments.”* Charlotte stated that she *“would not give them much of anything.”* She commented, *“A lot of nurses will just say, ‘I’m sorry we can’t give out any information, you will have to touch base with the family.’”* Less common responses of what information could be shared included assessment data, nutrition and fluid status and disease processes (see Table 4).

Participants more readily described information they considered confidential and therefore could not be shared. Most of the participants ($n = 10$) identified that they could not share any information that was considered socially stigmatic. Disease processes considered socially stigmatic included diagnoses of HIV, AIDS, cancer, substance abuse or sexually transmitted diseases. Gail recalled this story,

We had a case just last week where we were sure the family didn't know that the patient had HIV. So we had to be careful. I don't think it came across that we were being mean, I think we handled that well. So in that case, even though the person is their contact person by law, you can't tell them everything.

Table 4

Participant Perceptions of What is and is Not Confidential

Information That Could Be Shared (n)	Information That Should Not Be Shared (n)
Condition (12)	Condition (2)
Everything (with HCPOA) (12)	Nothing (unless with Immediate Family) (4)
Vital Signs Trends (5)	Vital Signs (5)
Location (4)	Patient Name & Location (8)
Resting/Asleep/Awake (4)	Physical Visibility (5)
Equipment (3)	Chart/Records (8)
Plan of care (3)	Treatment (1)
Lab Results (2)	Lab & Test Results (9)
Assessments (1)	Assessments (1)
Disease Processes (1)	Diagnosis (7)
Intake & Output (1)	Prognosis (2)
Nutrition (1)	Socially Stigmatic Diseases (10)
	Pictures (9)
	Medications (3)
	Past History (3)
	"Their story" & Family Dynamics (3)
	Personal Identification Information (2)
	MD Name (1)
	Skin Care (1)
	Substance Abuse/Illegal Behavior (1)

Hannah indicated she perceived socially stigmatic information as more protected than other health information. Lilly agreed saying, *“I think the HIV, I would probably be a little more protective of because that has to do with personal choices the patient’s made and or possibly made.”* Charlotte disagreed, *“Everything is supposed to be kept confidential. You think of it as needed to be more confidential. It’s actually in practice; everything is as confidential as that.”*

Federal legislation requires protected health information be released when the health and benefit of the public or private citizens is affected. Contrary to the legislation, Gail stated, *“I don’t think it works that way. I think I would be legally compelled to not say anything.”* Kristen specified that *“suicide and abuse”* required reporting. Janelle conveyed knowledge of HIPAA (Uses and Disclosures for Which an Authorization or Opportunity to Agree or Object is Not Required, 2002). She stated,

If it is affecting the health of another person, TB, things that the other person needs to look to see if they are contracting a disease too, it’s regulated; TB and communicable diseases that can be passed on. The health department requires that.

Also considered confidential were lab and other test results ($n = 9$) as well as the medical record ($n = 8$). Least stated information as confidential was assessments ($n = 1$), physician names ($n = 1$), skin care ($n = 1$) and treatments ($n = 1$). Hannah specified that confidential information included, *“if they have family issues, diagnosis, medication, what’s happening with them at that time, skin care, anything having to do with the patient.”* Table 4 lists participant responses of what is and is not confidential.

Nurses reported that giving or withholding information was dependent on certain factors. Anne recognized that occasionally information must be released in an effort to gain further information from family or visitors and to provide accurate and safe care. She noted

that often care is provided in urgent situations and release of information is necessary to obtain consent for procedures and other invasive treatments.

Another factor mentioned was the sharing of information on a “need to know” premise. Charlotte stated, “Confidentiality is based on need to know.” Hannah commented about information, *“it’s confidential to an extent because it’s needed for their care so you know, I have to let people know, healthcare workers know . . . to coordinate their care.”*

Lilly relayed that the amount of information released to ancillary healthcare workers was dependent on their role. She commented,

Phlebotomist, they don’t really need information about the patient other than their name and medical record number and what they need to draw. Sometimes the diagnostic areas like x-ray they may need to know a little bit more about patient diagnosis and what we’re looking for.

Five of the nurses noted that they shared more information when they were comfortable with the subject area. Beth stated, *“In fact, I don’t know that I would give any diagnosis unless it’s something like sepsis. I talk about sepsis . . . and how it’s affecting everything, but cancer, HIV, you know stuff like that, I separate those.”* Janelle relayed sharing information about hemoglobin and lab values when she felt the family expressed interest and demonstrated some level of understanding. When asked was there information that she was not comfortable sharing, Kristen replied,

Sometimes, yes and I don’t tell them. I gauge the situation and what’s going on and the person I’m talking to; what they can handle, what I think they need to hear and what they really want to and what would be best for them. I don’t lie to them . . . I just tell them what they need without telling them more than they need to hear.

Irene commented that she handled giving or not giving results or outcomes by remaining unaware of the information. She stated that she was honest with the family. *“Most of the time, I haven’t seen it [test results] because they’re done early in the morning and I don’t*

pull them up. Unless it's something critical, they don't call us so I tell them the truth." She further commented that she defers to the physician in those circumstances. *"I personally would never discuss them [results] with them, with the family because I am a nurse. I didn't order the lab. I feel like that's the doctor's responsibility."*

When asked how they handled sharing information in situations where they knew the results of a test for complex or potentially socially stigmatic disease, some nurses replied that they avoided the situation by deferring the question to the physician. Kristen replied, *"I would not give another family member that diagnosis. I wouldn't think that would be my place to do that . . . I would let the physician or the family member or the patient do that."* Irene replied, *"I say, I can't discuss that."*

Nurses avoid painful truths. Others said they lied to patients and family members when they knew test results and were not comfortable or able to give the results. Gail stated, *"Even if they ask me the question if he had HIV, I would just say I don't know."* Lilly stated that in these cases, she would say *"I don't know. I might say I don't have that result back or talk to the doctor to get those results."* Frances relayed this story,

Well, I've had [a] patient who had, we got patho results and I had to read them or I had to read a CT scan that showed a massive, massive head bleed and the family doesn't know about it yet. I can't tell them that information. I tell them, and you lie, the report's going directly to the physician I don't have access to that I'm sorry.

When asked how she felt about lying to patients and family members, Frances replied,

I'm ok with that part of it because it's not my place to tell them and it's not, it's out of my scope of practice. And I'm ok with that. I don't want to have to bring that bad news to somebody. I don't want to be that person.

Knowledge of North Carolina State Legislation

Lack of knowledge. Knowledge of N.C. law varied among participants. *"I don't know"* was the most common response ($n = 8$) when nurses were asked if N.C. had state

specific confidentiality legislation. Frances was unsure of specific legislation but noted that N.C. law was impacted by other regulation. ***“I’m sure they do with HIPAA and the NC Board of Nursing.”*** Evelyn demonstrated more detailed knowledge that at times, federal legislation supersedes state legislation. ***“I figure HIPAA covers. Between HIPAA and [hospital] practice it pretty much took care of what I needed to know.”*** Evelyn related her perception that N.C. has specific laws that define the flow of information. She stated, ***“... that is at least North Carolina if not beyond. It talks about next of kin as far as child and spouse first then child and parent and then going down the list.”*** Evelyn noted that she believed N.C. to have established common-law marriage legislation. ***“I think it’s seven years ... they call it common-law wife or common-law spouse and I think its seven years.”*** N.C. does not recognize long term relationships as legally binding, therefore long term partners or significant others are not the legal next of kin.

According to N.C.G.S § 8-53.13 (2004) communication between patients and nurses are considered privileged and indicates that no disclosure of patient-nurse communication should occur, except under direction of a superior or district court judge for purposes of justice (Nurse Privilege, 2004). None of the nurses verbalized knowledge of privileged communication legislation. Anne commented, ***“It’s not, I don’t think it is ... and yet there are some things that we have to be able to ask them to take care of them. There again there is that level of trust that is established.”*** When specifically asked, Irene indicated the most accurate perception. She stated, ***“You know I’ve never thought, I think it depends on what they say. With some, there are a lot of private things they disclose to us, but yes, I think as their caregiver that is privileged.”*** None of the nurses discussed or acknowledge duty to

warn legislation, the Declaration of Patient Rights (1997) or the patient's bill of rights (Notice to Patients, 1983).

Knowledge of North Carolina Board of Nursing and Patient Confidentiality

Setting the standard and “. . . hold[ing] us accountable.” The overriding theme related to the BON's role in relation to patient confidentiality was to set, uphold and monitor compliance and accountability to confidentiality standards and legislation. Slightly more than half ($n = 7$) of the nurses noted that the BON played some role in development of standards of practice. Beth stated the BON acts as a “*. . . spokesperson for nursing in general. It's an organization that has the best interest of patients and nursing at the bottom of it.*” Gail correctly describes the board's role regarding regulation, “*. . . when it comes to the board of nursing, they, I assume have a role in helping form the regulations around HIPAA.*” Irene noted that the practice of nursing was governed by “*The Nurse Practice Act, which I haven't read in 15 years.*” She continued to say, “*I have not read it, but I think nurses have always with their laws, been very mindful of the patient and always put the patient first, historically, since Florence Nightingale.*” Irene was the only participant to specifically name the nurse practice act or the historic figure of Florence Nightingale. None of the nurses spoke of the Florence Nightingale Pledge or the Hippocratic Oath normally associated with medicine.

All of the nurses relayed that the BON was involved in monitoring compliance with confidentiality legislation. Anne commented, “*The rules are HIPAA's . . . you do have to have your own profession monitoring what is acceptable standards within the profession.*” Charlotte and Irene agreed that the BON's role included holding nurses accountable to confidentiality legislation. Charlotte commented, “*I think the board of nursing would follow*

the HIPAA laws and would hold us accountable to those. Certainly, if there are other individual laws through the state, then the boards of nursing would hold us accountable to those also.”

Donna was firm in her knowledge of the board’s disciplinary role; *“I think the board of nursing takes a very strong stand on confidentiality and they would be very quick to make certain any nurse that broke confidentiality would be reprimanded up to and including taking away your license.”* Hannah agreed and further described the BON’s role as investigative as well as punitive. *“I feel that they do, from what I understand, a thorough investigation of what has happened and so they have basically recreated to see what happened and if you’re found guilty then they punish you harshly.”*

Knowledge of Institution-Specific Confidentiality Policy

Nurses were unfamiliar with institutional policy. Overwhelmingly, nurses were unfamiliar with institution-specific policy regarding patient confidentiality. When asked if her hospital had any specific policies related to confidentiality, Frances replied, *“I don’t believe they have.”* Lilly noted that her institution required employees to sign a confidentiality agreement and there were other specific policies in place but she was unfamiliar with what they were. She stated, *“We do, but don’t ask me exactly what they are. I know that we do.”* Kristen, Hannah, and Irene noted that they were only aware of HIPAA. Evelyn, Gail and Janelle only recalled their hospital’s policy on unauthorized computer access of their own or family members’ record.

Knowledge of Confidentiality Resources

Resources available. All of the participants were able to discuss and list resources that were available to assist them in decision making regarding confidentiality issues and

concerns. Eleven of the twelve nurses identified that they would use the chain of command as a primary resource when needed. The chain of command included members such as the charge nurse, middle management, the nursing or house supervisor or administrative coordinator (AC) as well as upper management. The second most highly consulted resource was the nurses' peers or co-workers ($n = 8$). The board of nursing ($n = 1$) and an ethics class ($n = 1$) were the least reported resources; also noted as an available resource was risk management departments ($n = 7$) and an ethics committee ($n = 5$). Table 5 provides a comprehensive list of perceived available resources.

Table 5

Participant Perceptions of Available Confidentiality Resources

Resources Available (n)
Chain of Command (11)
Peers (8)
Internet/Intranet (7)
Risk Management (7)
Ethics Committee (5)
Chaplain (4)
Physicians (3)
Board of Nursing (1)
Ethics Class (1)

Resources desired. Overwhelmingly, nurses were satisfied with their available resources related to patient confidentiality. Most nurses replied that they did not know of any other new or different resources other than those already available. Kristen stated that she would like to have hard copies of resources available in a box on her unit. Irene preferred to also take a related class. Beth relayed findings from a journal article she read that called for a

family care specialist to aid family members in gaining and interpreting information from physicians. She stated that this type of position is not currently available at her institution.

Knowledge of Ethical Obligations

Application without definition. All of the nurses described situations and statements that indicated use and application of ethical principles though none of the nurses referred to or discussed ethical theories such as deontology, Kantian or utilitarian ethics. None of the nurses used words such as autonomy, beneficence or other terms commonly associated with ethics or ethical principles. All of the nurses relayed statements or examples of allowing patients to make their own decisions about sharing personal health information. Statements such as, *“I think that the patient’s wishes should be the main thing”* (Beth) and *“I have an ethical obligation to the patient not to divulge any of that information and to let them give only the information that they would want their family members to know”* (Charlotte) demonstrate application of the principle of autonomy.

Throughout their discussions of patient confidentiality, all of the nurses referred to doing “what’s best” or in the “best interest” of the patient. While none of the nurses explicitly named the principle of beneficence their application of this principle were evident by such statements like, *“I want to do what’s best for the patient based on their wishes”* (Beth) and *“. . . we’re here to benefit the patient and that’s part of the ethical part of being a medical person”* (Janelle).

Nurses alluded to the concepts of fidelity and advocacy and for their patients in their discussion. Anne stated, *“It is just part of the profession that you are expected to advocate for the patient, show them dignity and respect.”* Janelle commented, *“It amazes me*

sometimes that they trust us as much as they do. I'm glad they do and I wouldn't want to do anything to break that trust . . ."

"Do unto others." When asked what ethics were involved with patient confidentiality, all of the nurses referred to "the golden rule" or treating patients as they would want to be treated in the same situation (reciprocity). Irene commented that it is ***"Just common sense. It's human nature. Do unto others as you'd have them do unto you."*** Gail stated, ***"You're always taught to be aware of yourself. If you were that person, how would you want to be treated? So you try to think that way."***

Kristen and Anne alluded to principles of Kantian ethics and doing what is right for the purpose of doing right. Anne relayed, ***"I am one of these people who really follows the rules . . ."*** She commented that she felt obligated to do the right thing because ***" . . . rules are made to protect people . . ."*** She did note that ***" . . . it works both ways, you just have to use some common sense."*** Similarly, Kristen stated ***"It's [confidentiality] just the right thing to do. I would want somebody to protect my privacy and not tell things about me . . . without my permission. It's just the right thing to do."***

Research Question 2: What Observations Do Critical Care Nurses Have Regarding Patient Confidentiality and its Application in Their Work Environment?

Differences between Units

Confidentiality is the same everywhere. When asked if confidentiality was different between ICUs and other types of units, seven of the nurses reported they felt that confidentiality was and should be the same, regardless of the type of unit or patient population. Frances and Anne reported having never worked on any other unit than ICU but didn't seem to think confidentiality was much different than in the ICU. Five nurses reported

that while confidentiality is the same, regardless of the type of unit, it is easier to maintain in the ICU setting. Hannah replied that one difference is semi-private rooms. She noted,

Everything that goes on with that patient, the other patient knows and if the family is in there, then they know. In the ICU, we are in [a] much better situation in that we have one patient per room so it's a lot better or easier to control than it is on the floors.

Donna and Irene commented that patient load impacted their ability to protect confidentiality more easily. Irene said, ***"I think it's easier for me to monitor what goes on with the patient because I have a small patient population whereas the floor nurses carry a lot of patients . . ."*** Donna similarly commented about floor nurses, ***"I think it is much tighter, you know in the ICU than like on the med/surg floor. I mean they have so many patients and they are constantly running and you can walk down a med/surg unit and you can hear them in the hallway."*** Lilly, Gail, and Janelle commented that monitoring patient confidentiality was easier in the ICU because of being ***" . . . a locked unit and being small so we can control who comes in and out and who gets what information"*** (Lilly).

Impact of Confidentiality Legislation on Practice

Nurses were able to distinguish some changes in practice from before HIPAA to after. Kristen stated that before HIPAA, ***"We didn't have all this secrecy before. Basically, I don't remember as much regulation of information and as many rules about and the regulation that we have now; the HIPAA policy and the privacy policy."*** Since enactment of HIPAA, all of the nurses discussed more observable controls of information and various methods of control of information including code words and the physical design of clinical units. When asked how she would respond regarding inquiries about a patient before HIPAA, Kristen replied, ***"I'd probably say she's not doing too good today. Instead, if you called me today, my first response would be 'do you have a code word?'"*** Lilly and Irene agreed that before

HIPAA, information was given more freely and since HIPAA, information is restricted to generic comments about condition. Charlotte shared a personal story. She commented that as a teaching tool for new employees, she would leave patients in her computerized care list.

... I would go in [the computer] and check and see how they were doing, how were their labs, how was their potassium. We don't do that any longer. We used to ask the physicians, 'how is Mr. so and so doing?' We rarely do that, if ever anymore.

Janelle commented the biggest difference she recalled is that before HIPAA, a breach of confidentiality might lead to a law suit or affect the nurse's job or evaluation. Beth stated that since HIPAA, *"I think the average nurse myself included has definite, I don't want to say fear but reservation about sharing information with anybody."* Hannah, Lilly, and Gail specifically discussed punishments for breach of confidentiality and that they are more cautious and vigilant in their daily practice. Donna commented that she didn't know how HIPAA had impacted her daily practice other than *"... it confirmed everything I have done to this point ... because the rules for me were already there and ingrained, so it was just a matter of following the rules."*

Confidentiality legislation is therapeutic. Therapeutic outcomes are generally conceived as positive in nature and enhancing of the health and well-being of the actors (critical care nurses, their patients and visitors) (Kjervik, 2002; Roberson, 2007; Roberson & Kjervik, 2008; Wexler & Winick, 1991a, 1992; Winick, 1996/1997; Winick & Wexler, 2003). When asked if they felt if current confidentiality legislation was helpful, nine of the nurses indicated that they felt HIPAA was helpful. Gail and Hannah felt that HIPAA educated the public and assisted in the public's understanding of confidentiality. She noted that HIPAA clarified the nurse's responsibility regarding confidentiality. Although, Donna felt that HIPAA reinforced what nurses already do. Charlotte, Lilly and Anne indicated that

HIPAA has limited the number of phone calls from people not authorized to receive information. Lilly stated that HIPAA had impacted her practice, ***“I think for the better. I think we probably did give out too much information in the past without actually knowing . . . who’s on the other end of the phone.”***

Anne, Frances, and Kristen felt that HIPAA served as an authority on which they could “blame” not giving information. ***“HIPAA’s helped us too, kind of gave us the out on a couple of things”*** (Frances). Anne commented that she refers to the law when asked for confidential information; ***“You are now able to say, ‘I’m sorry, but the law says this.’ You don’t have to say, ‘It’s none of your business’.”***

Confidentiality legislation is both therapeutic and anti-therapeutic. In opposition to therapeutic, anti-therapeutic outcomes are considered negative or diminutive of the well-being of the actors (Kjervik, 2002; Roberson, 2007; Roberson & Kjervik, 2008; Wexler & Winick, 1991a, 1992; Winick, 1996/1997; Winick & Wexler, 2003) and are the unanticipated or negative results of rules (Roberson, 2007; Wexler & Winick, 1992; Winick, 1996/1997; Winick & Wexler, 2003). None of the nurses indicated that HIPAA was not helpful or anti-therapeutic. Anne, Charlotte, and Janelle indicated that while HIPAA is helpful, it has also ***“... made things more difficult”*** (Charlotte). Charlotte further commented, ***“I do think overall they [legislative changes] have been for the better but they can make it difficult, especially in the critical care settings.”*** Anne commented, ***“It sort of puts a barrier there . . . so this spontaneity of dealing with family members and visitors is slowed somewhat. I don’t think that is a bad thing but it does put that little extra step in there.”*** Janelle added, ***“I also feel like it’s a heavy burden of government coming down and saying you have to do this, whereas we would do it anyway.”***

Nurses' Observations of Breach of Confidentiality

All of the nurses were able to describe or relate to a time when they felt their own or their patient's confidentiality was compromised or breached. Breaches of confidentiality were committed by critical care nurses or other health care providers within the critical care setting (including ward clerks and physicians).

Family/Visitor instigated breaches. Instigation of a breach was often by family members or visitors seeking information without proper permission from the patient or authorized family member or representative. Frances relayed her experience in a situation where the family requested information about a patient's terminal diagnosis be withheld from a patient who was capable of managing his own health information. Anne, Charlotte and Donna all relayed stories where visitors misrepresented themselves as family members or the HCPOA and were given confidential information by staff under false pretense. Donna's experience,

We believed her, everybody did. They believed that this was so and so's sister. We have been telling her a lot of information and we came to find out that she was really just a church member. She was her sister in God. Luckily, the family was understanding and they knew the person and they were okay with what we had said, but it could have been a lot worse.

Charlotte recalled a similar experience where family members from out of town misrepresented themselves as a HCPOA. Her experience began with a patient with a history of substance abuse and recent discharge from a rehab facility where he met and named a third party as his HCPOA. During his acute illness, the patient was unresponsive and ventilated. At one point during his hospitalization, the patient's mother and sister from out of town arrived and identified themselves as the HCPOA. Charlotte continued,

There were some very difficult issues because the mother and the sister seemed to be the persons who really were the more caring and had his best interests at heart. I

think there were times that we probably shared information with the mother and the daughter and yes, there was a breach of confidentiality, but in the long run as it turned out when he was awake again and could answer, that he indicated to us that no he did not want this other person to have the information, any further information. So we had probably made the right decisions all along but it did look like we were breaching confidentiality.

Employee instigated breaches. Nurses relayed stories of when confidentiality was inadvertently breached by nurses or staff members. Examples ranged from walking away from computer screens with patient records displayed and leaving paper charts unattended to information being overheard by visitors during report and sharing information with patients and family members while other visitors were present. Hannah and Donna both reported hearing conversations about patients while in the elevator and cafeteria. Lilly relayed a story where an inadvertent breach resulted in termination of the offending nurse. *“I know of one instance where a nurse mixed up two patients and went in a patient’s room and said the other patient’s name and started talking about medications . . . and the hospital felt that was a breach. She was fired.”*

Donna recalled a time when her own confidentiality was breached and how that impacted her practice as a nurse.

I was young and I had put my arm through a window, severed my brachial artery. And so they just talked about it throughout the hospital and I was moved from the emergency room to the OR, to the ICU and then to the floor. As you made all these transitions, ‘Oh yeah, I heard about you when you came in.’ It was just like everybody knew everything that was going on, and even though I was young at the time, and at the time was not a nurse, you know, I carried that through.

Anne and Evelyn both relayed stories where staff intentionally accessed information about co-workers. Anne commented,

I have seen employees on my unit looking up people’s information out of pure curiosity. The most benign being just to see have they had their baby yet. And they have asked me for access to an interesting patient’s information and I have said, ‘I

don't feel comfortable giving this to you.' And they have said, 'That's okay, I'll just get it after you leave from somebody else.'

Janelle relayed a story about when a physician and desk clerk breached confidentiality.

We had one of our desk clerks fired because the doctor came up and asked something about a patient that wasn't his patient and she looked it up for him and she was fired. He should have known better but I think that's something physicians have done through the years. . . . I'm sure [he] was not trying to get by with something but just, he probably knew the patient in some way and I don't think it damaged the patient.

Individual Application of Legislation and Ethics to Personal Practice

Vignette #1. Participants were given a vignette to elicit their knowledge of confidentiality legislation as related to information sharing with a non-relative visitor. Based on their knowledge of confidentiality legislation, six of the nurses gave no information to the visitor. Frances relayed, *"She legally has no access to information. I would ask right away does he have family members. We need his next of kin before we can give you any information."* Anne indicated *"Information sharing is give and take. It's hard to ask her for information and not share any information."* Like Anne, three of the participants indicated that they would give *some* information to the visitor. The remaining three nurses gave information *freely*. Evelyn relayed, *"At this point, she is the significant person because there is no one else. So yes, I would give information."* Beth indicated that given this scenario, *"I would have to get leadership involved. He needs nursing care and monitoring. He doesn't need a nurse who is concerned with all this."*

Vignette #2. Participants were given a scenario to elicit nurses' perception of confidentiality in response to a web-based patient information site. Majority ($n = 9$) of the nurses were opposed to the use of a web-based format for sharing patient information. Donna stated *"To me, it is nothing more than a medical MySpace™."* Charlotte was concerned

about the integrity of this form of communication, ***“I would see this as a real breach in confidentiality.”*** The remaining three participants were in favor of the web-based form of communication. ***“I think it is a form of support for the family members who have to deal”*** (Frances).

Nurses are trusting. This vignette also elicited the participant’s perception and application of confidentiality law when confronted with sharing confidential information about an unresponsive patient. Four of the nurses stated that they relied on the HCPOA or the next of kin. Charlotte stated that she gave general information ***“... until I got to know the family and got a feel for why they were really there.”*** Beth, Evelyn and Gail all agreed that they rely on other people and trust ***“... the person visiting them is telling the truth or not.”*** Beth agreed, ***“You just have to hope that person, the spokesperson for the patient is truly reflecting the best interest of the patient.”*** Hannah relayed, ***“As we do with all of our patients, we don’t know if they choose to post information online. Once we give them that information we just have to trust that she will do what’s in the best interest of the patient.”*** Lilly deferred the responsibility of sharing confidential information to the physician.

Confidentiality has a personal impact. Nurses’ personal ethical beliefs were evoked. Beth commented, ***“This is an ethical dilemma for the nurse if she is trying to honor and be an advocate for her patients. I think it would be very hard to give information and feel good about the information you are giving.”*** All of the participants discussed their application of “the golden rule” and their desire to treat patients as members of their own family.

Lack of trust leads to changed nurse/family relationships. Knowledge that the mother in the scenario was posting patient information on the web impacted the relationship

between the nurses and the patient's mother. Beth commented, *"I like sharing information. I like teaching them stuff and what to expect. If I couldn't trust her, that she was doing what was in her son's best interest, then I may become more distant."* Lilly was more specific, *"I think I would probably talk to her about what I felt was the right, the correct thing to do. I would say 'think about how you would feel in this situation' and respond that way."*

Research Question 3: How Do Critical Care Nurses Describe Their Roles Regarding Confidentiality in the ICU?

Perceived Nurse Roles

Nurses indicated that their roles included: caregiver or caretaker; monitor of self and others; protector; communicator; interpreter of information; mediator; and advocate. Anne stated,

... because we are caretakers, we are gate keepers. Uh, we are the standard. You know they say in those polls, nurses are one of the most, probably the most trusted profession. It is a big responsibility and we have to monitor ourselves, other people. It's not just that my stuff gets protected, but I feel that I need to be that protective to people in general. (Anne)

Donna relayed, *"I think I am very protective. I think I do take it on, almost as if they are my children of sort."* Beth indicated that she felt her role included that of mediator between patients and families and among family members. Similarly, others indicated they were advocates for their clients.

Charlotte, Hannah, and Lilly indicated that part of their role includes communicating with the patient, visitors and others who come to visit or telephone to inquire about the patient. In addition to communicator, Charlotte and Hannah indicated one of their roles was that of interpreter of information. Hannah stated that one of her roles is *"... interpreting information ... what the physician has discussed or what's going on with the patient, kind*

of taking that information and filtering it down to a place where the family can understand it and actually giving the family that information.”

Desired Roles

All of the participants were pleased with their roles as they defined them. When asked if she wished she had more roles or responsibility related to patient confidentiality, Kristen replied, *“Absolutely not. I don’t need any more roles or responsibilities in any area.”* Later, she expanded her comment and added that she would possibly consider having a bigger role in creating policy related to confidentiality.

Summary

The findings of this study suggest that critical care nurses are knowledgeable about HIPAA (federal) legislation but are not as familiar with N.C. state legislation or their own institutional policies regarding patient confidentiality. Nurses were able to identify nuances of HIPAA that indicated to whom and what information should and should not be shared and were able to identify resources that were available to assist them should the need arise. The nurses were able to identify the role of the BON as setting the standards for nursing practice and assuming the roles of professional monitor and disciplinarian when necessary. Only one nurse mentioned the Nurse Practice Act.

Nurses reported they perceived confidentiality to be the same, regardless of unit type or patient population. They did recognize that maintaining confidentiality seems to be easier in the intensive care setting as the nurses and other staff often have more physical control (locked units, passcodes) than other types of in-patient care units. The nurses perceived their professional roles related to confidentiality to be the same as their peers within and external

to the critical care unit. Majority of the nurses indicated that they did not wish to have additional roles.

All of the nurses related application of ethical principles through stories of patient situations and response to the vignettes however, none of the nurses specifically named ethical terms or theories. Overwhelmingly, nurses spoke of “the golden rule” when referring to their perception and application of confidentiality legislation. Their responses to “do unto others” or to think about what they would want if they were the patient indicates a strong sense of reciprocity and personalization of their values on their practice.

The nurses relayed stories from their practice both before HIPAA legislation and after. Most were able to recall some differences with one nurse stating that HIPAA only reinforced what she does and always has done. The stories of situations when confidentiality was breached indicated that nurses as a rule are trusting of people and when that trust is breached, it damages the nurse/patient/family relationship. While all of the nurses identified that HIPAA has been helpful (therapeutic) in their daily practice, some did indicate that on a case-by-case occasion that the legislation did prove a hardship in the provision of care (anti-therapeutic).

CHAPTER 5

DISCUSSION AND CONCLUSIONS

The purpose of this study was to explore critical care nurses perceptions and knowledge of patient confidentiality. In an effort to explore this purpose, twelve respondents were asked (a) what knowledge of legislation and ethics critical care nurses have related to confidentiality, (b) how do critical care nurses describe their roles regarding patient confidentiality and its application in their work environment, and (c) how do critical care nurses describe their roles regarding confidentiality in the intensive care unit (ICU)?

In addition to the specific questions and discussion related to the research questions, nurses were also given two vignettes that sought their response to clinical situations in an effort to gain insight about their knowledge and interpretation of confidentiality legislation and subsequently, application to their individual practice. Interpretation of findings from this study will be discussed in light of the synthesizing framework: Therapeutic Jurisprudence (TJ). Discussion is organized by research question and thematic findings. Also presented will be limitations of the study, implications for further research, nursing education and practice and final conclusions.

Discussion

Originally, TJ was intended to evaluate the therapeutic or anti-therapeutic effects of mental health legislation. The primary goal of TJ is to assess for and optimize therapeutic effects of rule or law and to minimize negative or anti-therapeutic effects (Finkelman &

Grisso, 1996; Hutchinson, 2002; Kjervik, 2002; Madden & Wayne, 2003; Schma et al., 2005; Roberson, 2007; Wexler, 1991b; Wexler & Winick, 1992; Winick, 1997; Winick & Wexler, 2003). TJ was a good fit for this study because it encouraged the evaluation of the impact of confidentiality legislation on the perceptions and knowledge that critical care nurses have of rules (confidentiality law, state and federal), which was the primary purpose of the study. Using TJ as the framework for this study also assisted in analyzing the therapeutic or anti-therapeutic outcomes of rules (confidentiality law, state and federal) on individual critical care nurses' practice as well as the relationships between critical care nurses, patients and families in their care.

Research Question 1: What Knowledge of Legislation and Ethics Do Critical Care Nurses Have Related to Confidentiality?

Nurses Are Knowledgeable about Confidentiality Legislation

The findings of this study are important as they are the first to begin to explore critical care nurses' knowledge of confidentiality legislation. The findings of this study are significant for hospital and nurse leaders in evaluating the process, effectiveness and extent of education regarding confidentiality legislation. Findings from this study indicated that nurses are generally knowledgeable about the Health Insurance Portability and Accountability Act (HIPAA) as the primary rule governing patient confidentiality. Participants clearly delineated knowledge of HIPAA restrictions as outlined in Subpart E of 45 C.F.R. § 164.500-534 (Privacy of Individually Identifiable Health Information, 2001). Their definitions of confidential patient information are similar to those presented in the literature (Cain, 1999).

While not specifically using the legal term “*in loco parentis*” (Latin for “in the place of a parent”), nurses were able to describe this concept in regard to who they share confidential information with in the absence of the patient. Lilly particularly demonstrated knowledge of this concept in her discussion of emancipated minors. This description indicates a more in-depth understanding of 45 C.F.R. § 164.502, Uses and disclosures of protected health information: general rules (2002). These findings are consistent with suggestions from the literature (Dimond, 1999; Lisseman, 2000) that nurses turn to patient families or representatives in the absence of the patient. Critical care nurses in this study also indicated they released information on a “need to know” basis indicating knowledge of HIPAA legislation that requires information to be released on a “minimally necessary” basis (Uses and Disclosures of Protected Health Information: General Rules, 2002). While none of the nurses mentioned the American Nurses Association (ANA) Code of Ethics, their practice of releasing only minimally necessary information is consistent with the ANA recommendation regarding the nurse’s role in patient confidentiality. This knowledge of legislation and consistency with current literature demonstrates the effectiveness of the education that these nurses received regarding confidentiality legislation.

This study is the first to identify critical care nurses’ perception of what information is and is not considered confidential. While it is impossible to consider every possible situation and detail of patient information, this study provides a list of items that the nurses in this study deem confidential. In addition to this information, patients and family members should be asked what information is considered confidential to them as individuals. Going forward, this should serve as a starting point for nurse leaders and policy makers when writing and revising confidentiality policy. While some nurses indicated knowledge of

required reporting legislation, other statements such as Gail's that she believed she would be legally compelled not to share information indicates a need for further education regarding required reporting legislation, both state and federal.

Nurses in this study indicated that shift report or rounds proved to be a time in which incidental breach of information occurred. These findings are similar to those found by other researchers (Kowalski et al., 2003; Rylance, 1999) who noted that information is often overheard by families and visitors. These findings indicate there may be a need for nursing leadership to evaluate current policies and to establish a plan of action regarding the coordination of shift report and visitation policies while keeping patient families involved in the care of their loved ones. The nurses in this study conveyed familiarity of incidental breach legislation as outlined by 45 C.F.R. § 164.502 (Uses and Disclosures of Protected Health Information: General Rules, 2002).

Nurses Lack Knowledge of North Carolina State Legislation

This study begins to fill gaps in the literature as to what nurses do or do not know about N.C. state legislation. Overall, nurses were unable to specify whether or not NC had specific confidentiality legislation but correctly assumed that HIPAA preempted state legislation where HIPAA was more stringent (45 C.F.R. §160.203, Preemption of State Laws: General Rule & Exceptions, 2002). Nurses in this study did not discuss the patient's bill of rights nor the requirement by N.C.G.S. §131E-120 (Notice to Patients, 1983) that the patient's bill of rights be publically displayed in all facilities. Irene indicated that she considers nurse-patient communication privileged but did not specify that it was a legal obligation as specified in N.C.G.S. § 8-53.13 (Nurse Privilege, 2004). These regulations are important to the practice of nursing in protection of patient rights and the legal commitment

to protect communication with patients. Protection of privileged information is important to support and maintain patients' autonomy. It is imperative for nurse leaders to recognize the importance of this legislation and to communicate these rights and privileges to nurses in direct care settings.

Nurses Know the BON's Role

This study is the first to explore critical care nurses knowledge of the BON's role related to patient confidentiality. The findings of this study indicate that nurses are aware of the BON's role in setting and upholding the standards of care related to nursing practice in N.C. as well as the disciplinary role engaged when a nurse breaches confidentiality. Only one nurse discussed the Nurse Practice Act (N.C.G.S. §90-9A) and further indicated she had not reviewed the Nurse Practice Act in 15 years. This finding should be cause for concern to leaders within the profession, nurse educators and administrators. Though federal legislation preempts that of state legislation regarding confidentiality, NC state legislation that governs nursing practice in N.C. is the Nurse Practice Act. For this reason, it is imperative that nurses be aware of these findings and make an effort to stay abreast of the legislation that guides nursing practice and any changes that impact patient care. Nurse leaders and educators should make mandatory the review of the nurse practice act and the regulations that guide and define the scope of nursing practice.

Nurses are Unfamiliar with Institutional Policy

Slutsman et al. (2005) noted that only 52% of physicians in their study reported being familiar with their organization's privacy policy. These findings are similar to the results of this study where overwhelmingly, the critical care nurses were unable to recall their institution's specific policy related to patient confidentiality. These findings are of interest to

staff educators and nurse leaders who develop and administer institutional policies. This lack of knowledge calls attention to the need for evaluation of current staff education practices.

Nurses' Perceived and Desired Resources

Nurses in this study were able to list resources they perceived available for their use. All but one indicated use of the “chain of command” and only one referred to the BON and another to an ethics course. The nurses in this study indicated satisfaction with their perceived resources and only one offered a suggestion based on current literature. Findings in Wagner and Ronen’s 1996 study indicated that Israeli nurses minimally relied on the hospital code of ethics (34%), the patient’s declaration of rights (44%) and only 31% of the nurses were familiar with the Israeli Code of Ethics for Nurses when confronted with an ethical dilemma. The findings in this study are consistent with the findings of that study in that none of the nurses in this study related that they used any of those as resources and those resources were in fact not mentioned in their discussion of patient confidentiality at all. The resources listed in the findings of this study serve as a building block for which clinical leadership could begin to assemble actual resources available and to consider those resources that were desired. Consideration should be given to encourage nurses to refer to the ANA Code of ethics, as well as the individual organization’s philosophy, mission statement and code of ethics where applicable.

Nurses Apply Ethical Principles

There is considerable research related to ethical decision making as a conscious effort but little examination of the intuitive ethical behavior of nurses. Nurses in this study applied deontological ethical principles as demonstrated by responses such as, “*the patient’s wishes should be the main thing*” (Beth). While it is evident that Beth is applying the principle of

autonomy, she never used the term in her discussions. None of the nurses named ethical principles or theories in their discussion of patient confidentiality or situations where ethics might be involved. Overwhelmingly, nurses identified their application of the golden rule when caring for patients where ethics became an issue. This application indicates a personalization and application of the deontological principle of beneficence through reciprocity.

Through a different lens, it could also be said the nurses were employing a form of virtue ethics: the ethics of care. The nurses descriptions of their interactions, relationships and actions on behalf of their patients indicate value placed on “intimate personal relationships, sympathy, compassion, fidelity, discernment and love” all of which are critical attributes of the ethic of care theory (Beauchamp & Childress, 2001, p. 369). The application of this theory seems to be without forethought and appears to be spontaneous and intuitive for this group of nurses as indicated by such responses as, “***Just common sense. It’s human nature***” (Irene). This is also indicative of virtue ethics in that the nurses’ responses seem to be based on their personal beliefs and values or character traits. This is one of the basic tenants of virtue ethics: acting based on personal characteristics and instincts as opposed to forced ethical principles (Athanassoulis, 2010, Hodkinson, 2008). Reynolds, Scott, and Austin (2000) relate this behavior potentially as empathy and perceived moral practice. It is difficult to apply the findings of this study to that of Reynolds et al. due to an unclear definition of empathy as a theory or as a basic emotion.

A surprising theme from this study was that nurses sometimes avoid painful truths. Many of the nurses stated that they avoided uncomfortable communication with family members by intentionally remaining unaware of information such as test results or diagnoses.

Frances stated that she sometimes lied to avoid sharing information. Were this 1883, Oliver Wendell Holmes, Sr. would agree encouraging clinicians to avoid using terms that may incite fear and are unknown to patients as they “will certainly look it out in a medical dictionary, if he does not interpret its dread significance on the instant” (p. 389). Other findings relating to what information is shared indicate that some nurses only share information they are comfortable discussing and share information based on their assessment of the individual’s ability to understand and process the information. Holmes would have agreed stating, “Your patient has no more right to all the truth you know than he has to all the medicine in your saddlebag . . . He should get only just so much as is good for him” (p. 388). Current literature debates the issue of truth telling as a dilemma between two ethical principles: veracity and beneficence. According to Littlejohn (1999) there may not be a right or wrong regarding truth telling as the right or wrong action can be approached and analyzed from several ethical theories and principles. Other literature (Laine & Davidoff, 1996) would strongly disdain the findings of this present study citing that patient centered care begins with an informed patient in collaboration with healthcare providers. The findings here suggest that these nurses are aware of their individual strengths and abilities to communicate information and are willing to engage in behavior that others may or may not approve of in an effort to maintain their professional relationship with the patient or family members. These findings are important for nurses engaged in daily bed-side practice to recognize the role values clarification and the impact their personal values have on their practice, as recommended by the ANA Code of Ethics (ANA, 2001). It is important for hospital leadership to consider the actions of the nurses in this study when planning resources for nurses in all areas of practice. Consideration should be given to resources that encourage nurses to explore their individual values

regarding truth telling or veracity and provide opportunities for nurses to engage in discussion of situations in which their personal ethics may impact the care they provide.

Research Question 2: What Observations Do Critical Care Nurses Have Regarding Patient Confidentiality and its Application in Their Work Environment?

Confidentiality Is the Same Everywhere

The findings of this study indicate that critical care nurses feel that confidentiality should be the same regardless of the type of unit but that it is seemingly easier to maintain in the ICU related to the workload of the nurses, control of visitation policies and the physical design of the unit. These findings are similar to those by other researchers (Karro et al., 2005; Kowalski et al., 2003) who indicate that confidentiality can be affected by the unit's physical design as well as visitation policies. Hannah indicated that maintaining confidentiality is easier in the ICU as opposed to other units as there is only one patient per room on her unit as opposed to other units where semi-private rooms are used. While these comparative studies did not take place in an adult ICU, the findings can be employed in the adult ICU as the principle of confidentiality is not age or population specific.

Confidentiality Legislation is Therapeutic

Currently, there is a vast amount of literature that surrounds HIPAA and nursing practice but no research that specifically examines the therapeutic or anti-therapeutic effect of confidentiality legislation on practice. Nurses in this study were able to distinguish changes in their practice since the enactment of HIPAA legislation in 2003. Majority of the nurses indicated they perceived the changes to have a therapeutic outcome for their patients and their individual practice. Examples of therapeutic outcomes of HIPAA legislation ranged from patients and family members being more educated and understanding about privacy

laws and policies to the nurses having someone to “blame” when they were confronted about sharing confidential information. Three of the nurses indicated that while they believed HIPAA legislation to be overall therapeutic they felt that the legislation was at times a “burden” and a “barrier” in relation to family member-nurse relationships and communication. These descriptions are parallel to findings by Woods et al. (2000) who noted that patients and caregivers reported that confidentiality was viewed as an obstruction or a barrier. Similar to statements by Roberts (2003), Donna commented that confidentiality legislation only reinforced her current practice and indicated no noticeable impact of confidentiality legislation. These findings are important to policy makers at all levels (both public and private) as they indicate the current path of legislative efforts to maintain the confidentiality of individuals is therapeutic and thus leading to positive outcomes (the ultimate goal of TJ).

Breach of Confidentiality is Still a Problem

Nurses indicated that breach of confidentiality was instigated by two parties: family members and visitors as well as employees. They reported that most of the breaches were related to inquiry by family members. This is consistent with findings by other researchers who also noted that breach of patient confidentiality often began with family members (Dimond, 1999; Trueman, 2000; Whetten-Goldstein et al., 2001). Nurses also reported stories of breach instigated by other health care professionals, from unit clerks to registered nurses and physicians. These findings are important in the light of TJ as nurses at the bed-side reported breaches of information even after enactment of HIPAA legislation. This gap between the intentions of HIPAA legislation and reports of continued breaches indicate that there is some work still necessary to educate the public about HIPAA legislation and the

intentions to protect the confidentiality of private health information. Kristen indicated the use of code words to control release of information over the telephone. Perhaps this concept could be implemented for all access to confidential information, both verbal and electronic. Anne indicated that employees have access to electronic information about patients other than those in their direct care although to access information about patients not in their direct care is considered a breach of confidentiality. Anne did not indicate ramifications or institutional policy related to breach of information. It is evident that organizational leadership and staff educators should increase efforts furthering the education of all employees, regardless of their role about confidentiality policies and practices available to protect the confidentiality of patient information. This gap between the therapeutic intent of confidentiality legislation and actual practice indicates a need for development and implementation of more stringent control and monitoring of confidentiality procedures at the point of care.

All of the participants implied knowledge of the BON's role related to disciplinary actions. They also conveyed knowledge of civil penalties for breach of information as outlined by 45 C.F.R. §160.402 (Basis for a Civil Money Penalty, 2000) as well as criminal penalties, defined by 42 U.S.C. §1320d-6 (Wrongful Disclosure of Individually Identifiable Health Information, 1996). It is knowledge of individual organizational policy that is need of attention by nursing leadership and staff educators.

Nurses' Application of Legislation and Ethics to Personal Practice

To assess their application of legislation and ethics to personal practice, critical care nurses were given two vignettes. The first vignette elicited nurses' knowledge of confidentiality legislation related to information sharing with a non-relative visitor. The

second vignette elicited nurses' perception of confidentiality in response to a web-based patient information site. The findings of this study are important in that they identify the challenge faced by nurses when confronted with a dilemma about with who, when, where and how information should or should not be shared. These findings begin to identify and explore critical care nurse's feelings about scenarios they may experience in the daily care of critically ill patients. The nurses in this study expressed concern regarding the communication they *should* provide and the information they *desired* to provide to patient families and significant others. The findings suggest that critical care nurses in bedside practice employ their knowledge as well as their personal values regarding confidentiality in the interaction and communication with their patients, family members and visitors. The critical care nurses related to the patient's right to privacy and autonomy while appreciating the family's need for information. This recognition of the families' need for information is congruent with findings by other researchers (DeJong & Beatty, 2000; Gelling & Prevost, 1999; Quallich, 2002). The nurses were torn between their desire to inform and include the family in the plan of care and protecting and advocating for the patient. Beth's statement that the nurse's concern should be the patient first is consistent with the ANA Code of Ethics (2001) and Lisseman's (2000) recommendation that nurses remember their primary responsibility is to the patient first, then the family.

In regard to a web-based patient information site, the nurses expressed concern for breach of confidentiality and discomfort and reluctance to share information with individuals who knowingly post confidential information on the internet. Nurses relayed no control of how information is used when shared with family in any situation. Trust was an issue and impacted the information shared and the nurse/family relationship. These findings are similar

to other researchers (Andershed & Ternestedt, 2000; Cochran, 1999; Lisseman, 2000; Meier, 2002; Quallich, 2002). Through the lens of TJ, these findings reinforce the importance of educating nurses about confidentiality legislation. Consistent with the ANA code of ethics (ANA, 2001), nurses should be encouraged to explore their own individual values and the impact of personal values on bedside practice and relationships with patients, families and visitors. In an effort to optimize positive or therapeutic outcomes of all confidentiality legislation and policy, it is essential for nurses to know and correctly apply the policy of their individual institution as well as HIPAA legislation.

Research Question 3: How Do Critical Care Nurses Describe Their Roles Regarding Confidentiality in the ICU?

The ANA as well as the NC BON defines confidentiality as a duty owed to the patient in the nurse-patient relationship. According to the ANA (2001), the nurse's role is to preserve, protect and support the patient's rights and welfare in regards to self-determination. While nurses have many roles, the ones specifically mentioned by the ANA and the NC BON in discussion of patient confidentiality include advocate, protector, safeguard, care provider, collaborator, communicator and promoter of patient confidentiality. Erickson (2005) carries the related role to also include privacy mentor to others through teaching and role modeling good behaviors. These roles are consistent with the roles described by the nurses in this study and suggest that the nurses have developed a familiarity of their responsibilities and duties, both legally and morally to their patients.

In summary, the findings of this study indicate that critical care nurses are generally knowledgeable about confidentiality legislation at the federal level, which in NC is the governing legislation over patient confidentiality. Nurses were most unfamiliar with state

specific legislation, individual organizational policy and the Nurse Practice Act. The nurses in this study conveyed that HIPAA legislation has been therapeutic and serves as a form of official support for practices already in place prior to legislative enactment. Nurses perceive this legislation valuable both professionally as well as personally. They implement the legislation into their practice but are oftentimes torn between what they know is required and what they personally feel is morally right. Application of ethical principles was evident through the nurses' responses to guided questions, stories and their reactions to the vignettes. The predominant theme of their actions and reactions to ethical stories and the vignettes indicated application of "the golden rule." The overall findings of this study indicate that nurses are comfortable with their role in trying to balance the application of the law with ethical practice that includes the patient and family into the plan of care.

Implications

Research

The findings of this research are important to the population of nurses in this study. While not generalizable, the findings can be transferable as readers may connect or relate their own perceptions and experiences with the findings of this study. This transferability warrants replication of this study to explore a sample and setting outside of central N.C. in an effort to explore the impact of location on nurses' perceptions and knowledge of confidentiality legislation and the impact these factors have on their practice (therapeutic or anti-therapeutic).

Further investigation of nurse reasoning and discretion to share or not share information would begin to fill gaps in current research, literature and education. Future research should focus on the decision making process at the bedside, where decisions are

made without much time to consider all of the legal nuances and ethical theories related to sharing or not sharing confidential health information. Consideration should also be given to the impact of one nurse's decision and action versus that of another on the nurse-patient-family relationship.

Qualitative findings often serve as the basis for quantitative research. Using the findings from this study, a quantitative exploration of nurses' knowledge and application of confidentiality legislation, policy and ethical theory would provide the opportunity to reach a larger, more diverse population. This approach would provide further knowledge of how nurses from a variety of practice types and geographic locations apply ethical theory in relation to federal and various local legislative constraints.

Using the framework of TJ, research that examines all of the actor's (physician, nurse, patient, family, and visitor) perception and knowledge of confidentiality legislation and application to bedside practice is warranted. This research focus would yield insight about the provider-receiver roles when sharing confidential information. Exploration of wanted vs. needed information, aptitude and ability to understand, ability to employ and accept confidentiality legislation and policy would provide further conceptualization of confidentiality and its presence and impact on acute care nursing practice.

Examining the therapeutic effects of the legislation will be necessary to explore the impact that education and exposure to confidentiality legislation and nursing ethics have on interpretation and application to individual nurse practice. This would assist in filling the gaps in current literature related to the therapeutic effects of confidentiality legislation and potentially lead to re-examination of current policy and act as a stimulus for change.

Practice

The findings of this study are important to bedside nurses in that they affirm that these nurses are knowledgeable about federal confidentiality legislation and understand legal as well as the moral duty to protect their patient's confidentiality. While breaches of information still occurred, the nurses in this study conveyed confidence in their ability to handle situations where immediate decisions were required to share or not share information. The nurses indicated they were torn between doing what was legally required and what they felt was right. Values clarification exercises and simulation of scenarios where nurses are called upon to make immediate decisions within the context of institutional policy and the ANA code of ethics would be helpful in minimizing uncertainty and potential breaches of their duty. Institutional leaders should consider the findings of this study in context of their staff education policy and procedure, both initial as well as continuing throughout employment. Increased access to legal and ethical resources and guides may aid in diminishing breaches of confidentiality.

Education

The findings of this study are influential to nursing education, both pre and post licensure. The nurses in this study were knowledgeable about the legislation and its general applicability in the critical care setting. The nurses in this study all had experience before and after HIPAA enactment in 2003, therefore all of their education related to HIPAA legislation likely came from institutional resources. The nurses demonstrated knowledge of the federal legislation as well as the BON's role related to confidentiality. While it was not the focus of this study to evaluate the efficacy of nursing education, based on the present findings, it can be hypothesized that the continuing education about confidentiality legislation provided to these

nurses was effective. It was noted that the nurses were not familiar with their organization's policies. Efforts should be made to increase education and familiarity of these policies and procedures. Availability of resources that provide information about confidentiality, the ANA code of ethics and the Nurse Practice Act should be readily available and presented in a variety of mediums to accommodate different learning styles.

Nursing education, pre-licensure can aid in these efforts by increasing the exposure that student nurses have to applying the principle of confidentiality in a variety of settings. Providing simulation and scenarios in a structured, safe environment would allow students to apply legislative requirements as well as ethical principles.

Limitations

The sample used in this study was 12 critical care nurses from central N.C. The experiences of nurses from other types of practice as well as other regions of the country are unknown. All of the nurses in this study were Caucasian, natural born citizens. The perceptions and knowledge of nurses from various cultures and races are not represented. Demographic data such as marital status, age and shift assignment were not the focus of this study and therefore their impact on the findings was not explored.

All of the nurses in this study began working in the ICU before HIPAA enactment and thus had a minimum of seven years of experience in dealing with clinical situations requiring knowledge and application of confidentiality legislation. The impact of years of experience and previous encounters with situations related to patient confidentiality were not part of the focus of this research. Nurses in this study were not asked about their previous education regarding confidentiality law or ethics. It is therefore unknown what level, type

and frequency of education about confidentiality legislation and ethical principles the nurses had.

Conclusions

The purpose of this study was to explore critical care nurses' perception and knowledge of patient confidentiality. Findings indicate that critical care nurses are knowledgeable of confidentiality legislation. Nurses indicated while they knew about HIPAA and the restrictions on their practice, they were not familiar with their institution's policy on confidentiality. Nurses were familiar with the BON's role in setting and enforcing standards of care, only one nurse talked about the Nurse Practice Act and then admitted she had not read the Act in 15 years. These nurses perceived HIPAA as therapeutic for their patients and provided support for their roles as protector and guardian of confidential information. These findings are reassuring that post licensure nursing education is providing adequate education about HIPAA and the requirements administered by the legislation. Further attention should be afforded to continued education about organizational policy and the standards set by the BON and the rules that govern the scope of practice for nurses in N.C.

Nurses demonstrated use of ethical principles and theories through their stories about situations that involved confidentiality and their reactions to the vignettes. The most prominent theme regarding ethical principles was that of reciprocity related to beneficence. The nurse's used the term "the golden rule." Their application of this principle was most evident in their reactions to the vignettes. Investigation into the impact of ethical values on decision making about what to share and not share as well as with who information is warranted.

Through the lens of TJ, it is evident that these nurses perceive confidentiality legislation as therapeutic and apply it in the protection of their patient's confidentiality. The findings of this study indicate that the application of confidentiality legislation in addition to nurses' moral values assist the nurse with the legal and ethical duty to protect patient confidentiality.

Appendix A
Recruitment Flyer



PROTECTING YOUR PATIENTS' CONFIDENTIALITY

VOLUNTEERS WANTED FOR A RESEARCH STUDY OF CRITICAL CARE NURSES' PERCEPTIONS OF PATIENT CONFIDENTIALITY

To participate you must:

- Be at least 25 years old.
- Have at least 6 years experience as a critical care nurse.
- Speak English

The purpose of this research study is to learn about critical care nurses' perceptions of patient confidentiality, before and after HIPAA enactment and their knowledge of confidentiality law and ethics. Participation requires partaking in a face to face interview and one follow up telephone interview.



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

This research (study # 09-1250) is being conducted under the supervision of Diane Kjervik, JD, RN, Professor and Division Chair in the School of Nursing, 528 Carrington Hall, CB #7460, Chapel Hill, NC 27599-7460. (919) 966-4269

Compensation will be provided for your time.

To learn more contact:
Angela Newman, MSN, RN
School of Nursing
336-817-4720

OR

anewman1@triad.rr.com

Appendix B
Demographic Data Form

Date: _____ Time: _____ Participant Pseudonym: _____

1. Are you male or female? _____
2. What is your marital status? _____
3. What is your age? _____
4. What is your ethnicity? _____
5. What is your level of education? _____
6. Do you have any certifications? _____
7. Are you employed full time or part time? _____
8. What is your current shift assignment? _____
9. What type of facility do you work in?
 - a. Teaching hospital v. community hospital)? _____
 - b. Is it large or small? (Do you know the number of beds?) _____
10. How long have you worked as a registered nurse? _____
11. How long have you worked as a critical care nurse? _____
12. Describe the general physical environment of your
unit. _____
13. Have you ever been a patient or a family member of a patient in a critical care
unit? _____
14. If you have been a patient or a family member, how long ago? _____

Appendix C

The University of North Carolina at Chapel Hill IRB Approval



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

OFFICE OF HUMAN RESEARCH ETHICS
Medical School Building 52
Mason Farm Road
CB #7067
Chapel Hill, NC 27599-7067
(919) 966-3113
Web site: chre.unc.edu
<https://my.research.unc.edu> for IRB status
Federalwide Assurance (FWA) #4801

To: Angela Newman
School of Nursing
CB:7460

From: Public Health-Nursing IRB


Authorized signature on behalf of IRB

Approval Date: 7/30/2009

Expiration Date of Approval: 7/29/2010

RE: Notice of IRB Approval by Expedited Review (under 45 CFR 46.110)

Submission Type: Initial

Expedited Category: 7.Surveys/interviews/focus groups,6.Voice/image research recordings

Study #: 09-1250

Study Title: Critical Care Nurses' Perceptions and Knowledge of Patient Confidentiality

This submission has been approved by the above IRB for the period indicated. It has been determined that the risk involved in this research is no more than minimal.

Study Description:

Purpose: To explore critical care nurses' perceptions of patient confidentiality and their knowledge of confidentiality law and ethics.

Participants: 30 critical care nurses in active practice in a critical care setting. Participants will be at least 25 years of age, able to speak English and have a minimum of six years experience as a critical care nurse. Gender and ethnic diversity will be sought. A sample size of less than 30 is anticipated.

Procedures: A naturalistic, qualitative design using open-ended questions and an interview guide (Appendix A) will be employed.

Investigator's Responsibilities:

Federal regulations require that all research be reviewed at least annually. It is the Principal Investigator's responsibility to submit for renewal and obtain approval before the expiration date. You may not continue any research activity beyond the expiration date without IRB approval. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.

When applicable, enclosed are stamped copies of approved consent documents and other recruitment materials. You must copy the stamped consent forms for use with subjects unless you have approval to do otherwise.

page 1 of 2

You are required to obtain IRB approval for any changes to any aspect of this study before they can be implemented (use the modification form at ohre.unc.edu/forms). Any unanticipated problem involving risks to subjects or others (including adverse events reportable under UNC-Chapel Hill policy) should be reported to the IRB using the web portal at <https://irbis.unc.edu/irb>.

Researchers are reminded that additional approvals may be needed from relevant "gatekeepers" to access subjects (e.g., principals, facility directors, healthcare system).

This study was reviewed in accordance with federal regulations governing human subjects research, including those found at 45 CFR 46 (Common Rule), 45 CFR 164 (HIPAA), 21 CFR 50 & 56 (FDA), and 40 CFR 26 (EPA), where applicable.

CC:Diane Kjervik, School Of Nursing



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

OFFICE OF HUMAN RESEARCH ETHICS
Medical School Building 52
Mason Farm Road
CB #7087
Chapel Hill, NC 27599-7087
(919) 965-3113
Web site: ohre.unc.edu
<https://my.research.unc.edu> for IRB status
Federalwide Assurance (FWA) #4801

To: Angela Newman
School Of Nursing
CB:7460

From: Public Health-Nursing IRB


Authorized signature on behalf of IRB

Approval Date: 6/24/2010
Expiration Date of Approval: 6/23/2011

RE: Notice of IRB Approval by Expedited Review (under 45 CFR 46.110)
Submission Type: Renewal
Expedited Category: 7.Surveys/interviews/focus groups,6.Voice/image research recordings
Study #: 09-1250
Study Title: Critical Care Nurses' Perceptions and Knowledge of Patient Confidentiality

This submission has been approved by the above IRB for the period indicated.

Study Description:

Purpose: To explore critical care nurses' perceptions of patient confidentiality and their knowledge of confidentiality law and ethics.

Participants: 30 critical care nurses in active practice in a critical care setting. Participants will be at least 25 years of age, able to speak English and have a minimum of six years experience as a critical care nurse. Gender and ethnic diversity will be sought. A sample size of less than 30 is anticipated.

Procedures: A naturalistic, qualitative design using open-ended questions and an interview guide (Appendix A) will be employed.

Investigator's Responsibilities:

Federal regulations require that all research be reviewed at least annually. It is the Principal Investigator's responsibility to submit for renewal and obtain approval before the expiration date. You may not continue any research activity beyond the expiration date without IRB approval. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.

When applicable, enclosed are stamped copies of approved consent documents and other recruitment materials. You must copy the stamped consent forms for use with subjects unless you have approval to do otherwise.

You are required to obtain IRB approval for any changes to any aspect of this study before they can be implemented (use the modification form at ohre.unc.edu/forms). Any unanticipated problem involving risks to subjects or others (including adverse events reportable under UNC-Chapel Hill policy) should be reported to the IRB using the web portal at <https://irbis.unc.edu/irb>.

This study was reviewed in accordance with federal regulations governing human subjects research, including those found at 45 CFR 46 (Common Rule), 45 CFR 164 (HIPAA), 21 CFR 50 & 56 (FDA), and 40CFR 26 (EPA), where applicable.

CC: Diane Kjervik, School Of Nursing

Appendix D

University of North Carolina-Chapel Hill Consent to Participate in a Research Study Adult Subjects Biomedical Form

IRB Study #_09-1250_____

Consent Form Version Date: June 22, 2010_____

Title of Study: Critical Care Nurses' Perception and Knowledge of Patient Confidentiality

Principal Investigator: Angela Newman, MSN, RN

UNC-Chapel Hill Department: School of Nursing

UNC-Chapel Hill Phone number: 919-966-4269

Email Address: abnewman@email.unc.edu

Faculty Advisor: Diane Kjervik, **JD, RN, FAAN**
Professor and Division Chair
528 Carrington Hall, CB #7460
Chapel Hill, NC 27599-7460
(919) 966-4269

Funding Source and/or Sponsor: None

Study Contact telephone number: 336-817-4720

Study Contact email: abnewman@email.unc.edu

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary.

You may refuse to join, or you may withdraw your consent to be in the study, for any reason.

Research studies are designed to obtain new knowledge that may help other people in the future.

You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Deciding not to be in the study or leaving the study before it is done will not affect your relationship with the researcher, your health care provider, or the University of North Carolina-Chapel Hill. If you are a patient with an illness, you do not have to be in the research study in order to receive health care.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

The purpose of this research study is to learn about critical care nurses' perceptions of patient confidentiality, before and after HIPAA enactment and their knowledge of confidentiality law and ethics.

You are being asked to be in the study because you practice nursing and have at least six years experience as a registered nurse in a critical care setting.

Are there any reasons you should not be in this study?

You should not be in this study if you have been a nurse for less than six years and are less than 25 years old.

How many people will take part in this study?

If you decide to be in this study, you will be one of less than 30 people in this research study.

How long will your part in this study last?

Your interview will last for approximately one hour. One follow-up interview will be included, which will last for approximately 30 minutes. The follow-up interview can be completed in person or by telephone, whichever is most convenient for you. There may be a couple of weeks between your initial interview and being contacted for the 15 minute interview. Therefore, your participation in this study will last about 3-4 weeks with the one hour interview and 15-30 minute follow-up interview being the actual activities.

What will happen if you take part in the study?

The interview will take place at a location of your choice; some suggestions are a private or secluded area of book stores, coffee shops or your home. You will be asked some questions about your perceptions and knowledge of patient confidentiality. There is no right or wrong answers, so I want you to answer the questions as honestly as possible and to the best of your ability. This interview will last for approximately one hour. With your permission I will be tape recording this interview. You can ask for the tape recorder to be turned off at anytime during the interview. If you do not want to be recorded you will not be able to participate in the study. The questions will be about your views of patient confidentiality in critical care units, your knowledge of patient confidentiality ethics and legislation, and your observations about patient confidentiality before and after HIPAA enactment as well as your observations about the implementation of confidentiality legislation and ethics in your practice and the practice of other nurses in critical care units. You will be asked to participate in one 30 minute follow-up visit or telephone conversation, which ever is most convenient for you. You may refuse to answer any of the questions I ask during these interviews. I will not share any information I hear unless there is indication that you are at risk and in need of help.

What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. You will not benefit personally from being in this research study. Interviewing you about your perceptions about patient confidentiality will assist researchers and clinicians to better understand patient confidentiality in the critical care environment and add to existing literature about patient confidentiality and confidentiality legislation.

What are the possible risks or discomforts involved with being in this study?

There are no known or anticipated risks for you to participate in this study. However, recalling some information may result in emotional distress. If this does occur, I will make the appropriate referral to get you the needed help. In addition, there may be uncommon or previously unknown risks that might occur. You should report any problems to the researchers.

How will your privacy be protected?

Your privacy and the confidentiality of the information you provide are very important. Privacy and confidentiality will be maintained by assigning pseudonyms that can only be identified by me. In order to contact you for the follow-up telephone interview, your name, telephone number and assigned pseudonym will be maintained on a list that will be kept in a locked cabinet until your interviews are complete. After the interviews are concluded, your name and any identifying information will be destroyed. At no time, will your name or contact information be assigned to what you say during your interview. Participants will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of

the University, research sponsors, or government agencies for purposes such as quality control or safety.

Your interview will be audio taped by the use of a digital recorder. After our interview, another person who has signed a confidentiality statement will transcribe what you said to me. After transcription of the tape, it will be immediately destroyed. When not in use, your taped interview will be locked in a cabinet only accessible by me. I will not share any information I hear unless there is indication that you are at risk and need help. Transcripts of the interviews and my notes will be encrypted and stored on a password protected hard drive and mass storage disk. The audio tape will remain in my possession at all times except during the transcription process.

Check the line that best matches your choice:

_____ OK to record me during the study

_____ Not OK to record me during the study

What if you want to stop before your part in the study is complete?

You can withdraw from this study at any time, without penalty. The investigators also have the right to stop your participation at any time. This could be because you have had an unexpected reaction, or have failed to follow instructions, or because the entire study has been stopped.

Will you receive anything for being in this study?

You will be receiving a gift card in the amount of less than \$25.00 in appreciation for taking part in this study.

Will it cost you anything to be in this study?

It will not cost you anything to participate in this study.

What if you are a UNC employee?

Taking part in this research is not a part of your University duties, and refusing will not affect your job. You will not be offered or receive any special job-related consideration if you take part in this research.

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions, or if a research-related injury occurs, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research subject?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Title of Study: Critical Care Nurses' Perceptions and Knowledge of Patient Confidentiality

Principal Investigator: Angela Newman, MSN, RN

Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

Signature of Research Subject

Date

Printed Name of Research Subject

Signature of Research Team Member Obtaining Consent

Date

Printed Name of Research Team Member Obtaining Consent

Appendix E

Critical Care Nurses' Perceptions and Knowledge of Patient Confidentiality Interview Guide

1. When you hear the words *patient confidentiality*, what do you think of?
2. Tell me what you think the most important features or aspects of patient confidentiality are.
3. Which of these is MOST important and why?
4. On the unit where you work, what roles are nurses expected to play in terms of patient confidentiality?
5. Do you think the expectations are the same on other critical care units?
6. Do you agree with these roles or wish you had other roles? If yes, what role do you wish the critical care nurse could have?
7. How do hospital rules or policies impact your implementation and interpretation of confidentiality laws and ethical obligations?
8. Is patient confidentiality different in the critical care unit than in other units?
 - a. If so, how and why?
 - b. If not, why?
9. Do you know of any laws that govern patient confidentiality and if yes, what are they?
10. How does HIPAA impact patient confidentiality in the critical care unit?
11. What was your practice like, before HIPAA?
 - c. Tell me a story about a patient situation related to confidentiality that you remember before HIPAA came about.
12. How has it changed since HIPAA was enacted?
 - d. Tell me a story about a patient situation related to confidentiality that you remember since HIPAA was enacted.
13. Does NC have any laws specific to patient confidentiality that are different from HIPAA and if yes, how do you feel about these laws and why?
14. What role and impact do you believe the NC Board of Nursing has on patient confidentiality?

15. Tell me about ethical obligations that are related to patient confidentiality and how they impact your practice.
16. Tell me a story about a time when you felt that patient confidentiality was compromised.
17. How do you think the situation should have been handled?
18. What resources are available to help you or guide you with questions regarding confidentiality and your legal and ethical obligations?
19. If you feel you would need other resources, what resources would you like to have
20. Tell me what you would do in this situation.

In your critical care unit, you are taking care of a patient who was in a single car accident. The patient was the driver and the only victim found at the scene of the crash. A woman who was driving by and saw the crash called 911. The patient was admitted to your critical care unit at 0300 that morning and was brought alone to the emergency room by EMS. He has suffered major internal injuries and a subdural hematoma, rendering him unconscious at this time. He has been identified by his state of Ohio driver's license but has no other personal belongings and has had no visitors.

At 1000, a woman comes into the unit and asks to see your patient. She identifies herself as the person who called 911 and also the patient's live-in girlfriend. They had been celebrating her birthday the evening of the crash and were traveling home at the time of the crash. After she introduces herself, she begins to ask questions regarding his condition, how do you proceed and why?

21. Tell me your thoughts and feelings regarding this situation.

Starting Monday, your unit will begin to offer a free website service that provides an opportunity for patients and families to:

- Post and receive news updates - concerned family members and friends can access the most recent news about the patient.
- Post and receive messages - loved ones may leave messages at anytime, from anywhere, in a way that provides support and isn't a burden.
- Share patient information - the personal and secure website contains important contact information and healthcare facility visiting hours.
- Post photos - create a photo gallery to share photos with friends and family.

The patient in the previous scenario has now begun to slightly improve and has been able to provide his mother's name, she lives in Ohio. Although more alert, the patient continues to remain unstable and has frequent bouts of confusion, delirium and combativeness. Upon notification, his mother immediately comes to North Carolina and holds vigil at his bedside in the ICU.

Unfortunately, the patient's condition deteriorated over the weekend and he is again unresponsive. Meanwhile, the patient's mother has taken advantage of the now available and free website service to update his friends and family who live in Ohio regarding his condition and photographs of his injuries. She has asked you to keep her informed of any and all information and updates that she may provide to others who are concerned. What are your thoughts and feelings regarding this scenario?

Appendix F

Confidentiality Agreement

I _____, do hereby agree to maintain confidential, all information contained within the audio recorded interviews and the transcriptions of said interviews. I do hereby certify that the information contained within the transcribed interviews is accurate to the best of my abilities. By signing this document, I promise to hold confidential and private any and all information obtained throughout my involvement with this project.

Your signature below certifies that the above statement is true and accurate.

Date: _____

Sign: _____

REFERENCES

- Access to Health Information*. (2004). N.C.G.S. § 130A-476.
- Affirmative Defenses*. (2009). 45 C.F.R. 160.410.
- American Medical Association. (2001). *Principles of medical ethics*. Retrieved from <http://www.ama-assn.org/ama/pub/category/2512.html>
- American Medical Association. (2011). *Patient confidentiality*. Patient-Physician Relationship Topics. Retrieved from <http://www.ama-assn.org/ama/pub/physician-resources/legal-topics/patient-physician-relationship-topics/patient-confidentiality.page>
- American Nurses Association. (2001). *Code of ethics for nurses with interpretive statements*. Retrieved from <http://www.nursingworld.org/MainMenuCategories/EthicsStandards/CodeofEthicsforNurses/Code-of-Ethics.aspx>
- American Nurses Association. (2011). *Florence Nightingale Pledge*. Retrieved from <http://www.nursingworld.org/FunctionalMenuCategories/AboutANA/WhereWeComeFrom/FlorenceNightingalePledge.aspx>
- Andershed, B., & Ternestedt, B. (2000). Being a close relative of a dying person: Development of the concepts “involvement in the light and in the dark.” *Cancer Nursing*, 23(2), 151-159.
- Applebee, G. (2006). A brief history of medical professionalism—and why professionalism matters. *Contemporary Pediatrics*, 23(10), 53-64.
- Athanassoulis, N. (2010). *Virtue ethics*. The Internet Encyclopedia of Philosophy. Retrieved from <http://www.iep.utm.edu/virtue>
- Basis for a Civil Money Penalty*. (2000). 45 C.F.R. §160.402.
- Beauchamp, T., & Childress, J. (2001). *Principles of biomedical ethics* (5th ed.). New York: Oxford University Press.
- Bloomberg, L., & Volpe, M. (2008). *Completing your qualitative dissertation: A roadmap from beginning to end*. Thousand Oaks, CA: Sage.
- Bouvia v. Superior Court*, 179 Cal. App. 3d 1127, 1135-36, 225 Cal. Rptr. 297. (Ct. App. 1986), review denied (Cal. June 5, 1986).
- Brink, P., & Wood, M. (1998). *Advanced design in nursing research* (2nd ed.). Thousand Oaks, CA: Sage.

- Burkhardt, M., & Nathaniel, A. (2008). *Ethics and issues in contemporary nursing* (3rd ed.). Canada: Thomas West.
- Cain, P. (1999). Respecting and breaking confidences: Conceptual, ethical and educational issues. *Nurse Education Today*, 19, 175-181. doi:10.1016/S0260-6917(99)80002-1
- Caplan, A. (1995). Donors don't need to give up privacy, too. In *Ethical issues in medicine and the life sciences*. New York: John Wiley and Sons.
- Clark, A. (2004, January 2). What's all the HIPAA hype? *Nurse Practitioner*, 2004 *Sourcebook*, pp. 6-11. Retrieved from www.tnpj.com.
- Cochran, M. (1999). The real meaning of patient-nurse confidentiality. *Critical Care Nursing Quarterly*, 22(1), 42.
- Components of Nursing Practice for the Registered Nurse*. (2002). 21 NCAC § 36.0024 (g) (4). In *RN Rules*. Retrieved from <http://ncbon.com/>
- Confidentiality of Patient Information*. (1994). N.C.G.S § 131E-97.
- Confidentiality of Records*. (1997). N.C.G.S § 143B-139.6.
- Confidentiality of Records*. (2002). N.C.G.S § 130A-143.
- Confidentiality of Records*. (2006). N.C.G.S § 130A-12.
- Creswell, J. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Daley, L. (1984). The perceived immediate needs of families with relatives in the intensive care setting. *Heart & Lung*, 13(3), 231-237.
- De Jong, M., & Beatty, D. (2000). Family perceptions of support interventions in the intensive care unit. *Dimensions of Critical Care Nursing*, 19(5), 40-47.
- Declaration of Patient Rights*. (1997). N.C.G.S § 131E-117.
- Definitions*. (2006). 45 C.F.R. § 160.103.
- Definitions*. (2009). 45 C.F.R. 164.402.
- Derse, A. (1999). Law and ethics in emergency medicine. *Emergency medicine clinics of North America*, 17, 307-325.
- Dimond, B. (1999). Confidentiality11: Terminal illness and the duty of confidentiality. *British Journal of Nursing*, 8, 1458-1459.

- Doe v. Methodist Hospital*. (1997). 690 N.E.2d. 681.
- Dracup, K., & Bryan-Brown, C. (2004). The law of unintended consequences. *American Journal of Critical Care*, 13(2), 97-99.
- Eisenstadt v. Baird*. (1972). 405 U.S. 438, 453; 92 S.Ct. 1029, 1038; 31 L.Ed.2d 349.
- Ellenchild-Pinch, W. J. (2000). Confidentiality: Concept analysis and clinical application. *Nursing Forum*, 35(2), 5-16.
- Emancipation*. (1998). N.C.G.S § 7B-35.
- Erickson, J. I. (2005). Caring for patients while respecting their privacy: Renewing our commitment. *Online Journal of Issues in Nursing*, 10(2), 77-94.
- Erlen, J. A. (2004). HIPAA—Clinical and ethical considerations for nurses. *Orthopaedic Nursing*, 23, 410-413.
- Finkelman, D., & Grisso, T. (1996). Therapeutic jurisprudence: From idea to application. In *Law in a therapeutic key: Developments in therapeutic jurisprudence* (pp. 587-595). Durham, NC: Carolina Academic Press.
- Flores, J. A., & Dodier, J. (2005). HIPAA: Past, present and future implications for nurses. *Online Journal of Issues in Nursing*, 10(2), 131-147.
- Florida Department of Health. (2011). *License verification*. Retrieved from <http://ww2.doh.state.fl.us/IRM00PRAES/PRASLIST.ASP>
- Furrow, B., Greaney, T., Johnson, S., Jost, T., & Schwartz, R. (2001). *Bioethics: Health care law and ethics* (5th ed.). Saint Paul, MN: Thomas West.
- Gelling, L., & Prevost, T. (1999). The needs of relatives of critically ill patients admitted to a neurosciences critical care unit: A comparison of the perceptions of relatives, nurses and doctors. *Care of the Critically Ill*, 15(2), 53-58.
- General Rule and Exceptions*. (2002). 45 C.F.R. § 160.203.
- Grbich, C. (2007). *Qualitative data analysis: An introduction*. London: Sage.
- Griswold v. Connecticut*. (1965). 381 U.S. 479, 85 S. Ct 1678, 14 L. Ed.2d 510.
- Harman, L. B. (2005). HIPAA: A few years later. *Online Journal of Issues in Nursing*, 10, 95-110.
- Health Care Facilities and Services*. (1973). N.C.G.S. §131E.

- Henneman, E., & Cardin, S. (2002). Family centered critical care: A practical approach to making it happen. *Critical Care Nurse*, 22(6), 12-19.
- Hodkinson, K. (2008). How should a nurse approach truth-telling? *Nursing Philosophy*, 9, 24-256. doi: 10.1111/j.1466-769X.2008.00370.x
- Hoepfl, M. (1997). Choosing qualitative research: A primer for technology education researchers. *Journal of Technology Education*, 9. Retrieved December 8, 2007, from <http://scholar.lib.vt.edu/ejournals/JTE/v9n1/hoepfl.html>
- Holmes, O. W. (1883). The young practitioner. In *Medical Essays, 1842-1882* [Riverside ed.] (pp. 370-395). Boston: Houghton Mifflin & Co. Retrieved from <http://www.archive.org/stream/medicalessays1896holm#page/n0/mode/2up>
- Hsieh, H., & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15, 1277-1288. doi:10.1177/1049732305276687
- Huberman, A., & Miles, M. (1994). Data management and analysis methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 428-444). Thousand Oaks, CA: Sage.
- Hutchinson, K. (2002). Forensic nursing practice viewed through a therapeutic jurisprudence lens. *Journal of Nursing Law*, 8(4), 23-29.
- Iseron, K. (1999). Principles of biomedical ethics. *Emergency medicine clinics of North America*, 17, 283-306.
- Karro, J., Dent, A., & Farish, S. (2005). Patient perceptions of privacy infringements in an emergency department. *Emergency Medicine Australia*, 17(2), 117-123. doi: 10.1111/j.1742-6723.2005.00702.x
- Kelly, C., Murray, F., Hamill, J., Quick, J., Spears, C., Lan, I., . . . Sayeed, H. A. (2002). HIPAA compliance: Lessons from the repeal of Hawaii's Patient Privacy Law. *Journal of Law, Medicine & Ethics*, 30, 309-312.
- Key, J. (1997). Module R14 Qualitative Research. In *Research Design in Occupational Education*. Retrieved from <http://www.okstate.edu/ag/agedcm4h/academic/aged5980a/5980/newpage21.htm>
- Kirchhoff, K. T., Walker, L., Hutton, A., & Spuhler, V., Cole, B. V., & Clemmer, T. (2002). The vortex: Families' experience with death in the intensive care unit. *American Journal of Critical Care*, 11(3), 200-210.
- Kjervik, D. (1999). Therapeutic jurisprudence and nursing law. *Journal of Nursing Law*, 6(3), 5.

- Kjervik, D. (2002). TJ and nursing. *Journal of Nursing Law*, 8(4), 19-22.
- Kjervik, D. (2005). Therapeutic jurisprudential analysis of the impact of policy decisions on nursing. *Journal of Nursing Law*, 10(3), 171-176. (Reprinted from 2003, *Nursing and Health Policy Review*, 2, 35-42).
- Knopp, R. K., & Satterlee, P. A. (1999). Confidentiality in the emergency department. *Emergency Medicine Clinics of North America*, 17(2), 385-396.
- Kowalski, W., Lawson, M., & Oelberg, D. (2003). Parent and nurse perceptions of confidentiality, rounding and visitation policy in a neonatal intensive care unit. *Neonatal Intensive Care*, 16(3), 46-50.
- Kuczynski, K., & Gibbs-Wahlberg, P. (2005). HIPAA the health care hippo: Despite the rhetoric, is privacy still an issue? *Social Work*, 50, 283-287.
- Kuzel, A. (1999). Sampling in qualitative inquiry. In B. F. Crabtree & W. L. Miller (Eds.), *Doing qualitative research* (2nd ed., pp. 33-45). Thousand Oaks, CA: Sage.
- Laine, C., & Davidoff, F. (1996). Patient-centered medicine: A professional evolution. *JAMA*, 275, 152-156. doi: 10.1001/jama.1996.03530260066035
- Legal Dictionary. (2008). *In loco parentis*. Law Dictionary. Retrieved from <http://www.law-dictionary.org/ld.asp?q=in+loco+parentis>
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Lisseman, I. (2000). Maintaining confidentiality and information-giving in intensive care. *Nursing in Critical Care*, 5(4), 187-193.
- Littlejohn, J. (1999) Ethics corner. Lying, deceit, fraud . . . do they ever belong in your nursing practice? *Maryland Nurse*, 18(3), 5-6.
- Lucas, B., & Adams, S. (2004). Roadmap to HIPAA: Keeping occupational health nurses on track. *AAOHN*, 52(4), 169-179.
- Madden, R., & Wayne, R. (2003). Social work and the law: A therapeutic jurisprudence perspective. *Social Work*, 48(3), 338-347.
- Marshall, M. (1996). Sampling for qualitative research. *Family Practice*, 13, 522-525. doi:10.1093/famp/13.6.522
- Mayring, P. (2001). Qualitative content analysis. *Forum: Qualitative Social Research*, 1(2). Retrieved from <http://217.160.35.246/fqs-texte/2-00/2-00mayring-e.pdf>

- Meer, D., & Vandecreek, L. (2002). Cultural considerations in release of information. *Ethics & Behavior*, 12, 143-156.
- Meier, E. (2002). Medical privacy and its value for patients. *Seminars in Oncology Nursing*, 18(2), 105-108. doi:10.1053/sonu.2002.32507
- Mental Health Service Providers; Duty to Protect Third Parties; Immunity*. (2005). Va. Code Ann. § 54.1-2400.1.
- Miles, M., & Huberman, A. (1994). *Qualitative data analysis* (2nd ed.). Thousand Oaks, CA: Sage.
- Neill, J. (2007). *Qualitative versus quantitative research: Key points in a classic debate*. Retrieved from <http://wilderdom.com/research/QualitativeVersusQuantitativeResearch.html>
- NewsMax.com Staff. (2006, July 15). Jeb Bush backs Terri Schiavo nurse. *NewsMax.com*. Retrieved from <http://archive.newsmax.com/archives/ic/2006/7/15/211727.shtml>
- North, M. (2002). *Greek medicine: The Hippocratic Oath*. Retrieved from http://www.nlm.nih.gov/hmd/greek/greek_oath.html
- Notice of Privacy Practices for Protected Health Information*. (2002). 45 C.F.R. § 164.520.
- Notice to Patients*. (1983). N.C.G.S § 131E-120.
- Nurse Privilege*. (2004). N.C.G.S § 8-53.13.
- Office for Civil Rights. (2011). *Health Information Privacy*. Retrieved from <http://www.hhs.gov/ocr/privacy/index.html>
- Outpatient Commitment; Examination and Treatment Pending Hearing*. (2004). N.C.G.S. § 122C-265.
- Owen, R. (2000). *A history and overview of HIPAA*. Retrieved June 25, 2008, from <http://www.hipaadvisory.com/regs/hipaahistorybyzon.htm>
- Owens, R. (1982). Methodological rigor in naturalistic inquiry: Some issues and answers. *Educational Administration Quarterly*, 18(2), 1-21. doi:10.1177/0013161X82018002002
- Paladichuk, A. (1998). Daphne Stannard, RN, PhD, CCRN: Families and critical care. *Critical Care Nurse*, 18(4), 86-91.
- Physical Safeguards*. (2000). 45 C.F.R. 164.310.

- Physician-patient & Nurse Privilege Waived in Child Abuse; Disclosure of Information in Impaired Driving Accident Cases. (2006). N.C.G.S § 8-53.1.
- Poland, B. (2002). Transcription quality. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research: Context & method* (pp. 629-649). Thousand Oaks, CA: Sage.
- Polit, D., & Hungler, B. (1997). *Essentials of nursing research methods, appraisal and utilization* (4th ed.). Philadelphia: Lippincott.
- Preemption of State Laws: General Rules and Exceptions*. (2002). 45 C.F.R. § 160.203.
- Privacy of Individually Identifiable Health Information*. (2001). 45 C.F.R. §164.500-534.
- Public Welfare*. (2000). 45 C.F.R. §§ 160-164.
- Quallich, S. (2002). Issues of confidentiality. *Urologic Nursing*, 22, 340-342.
- Reynolds, W., Scott, P., & Austin, W. (2000). Nursing, empathy and perception of the moral. *Journal of Advance Nursing* 32(1), 235-242. doi: 10.1046/j.1365-2648.2000.01440.x
- Rivas, J. D., & Sulmasy, D. P. (2002). Sexually transmitted disease: A private matter? *American Family Physician*, 66, 1351-1355.
- Roberson, A. (2007). *The experiences of adolescents consenting to psychiatric mental health treatment*. Unpublished doctoral dissertation, School of Nursing, University of North Carolina at Chapel Hill.
- Roberson, A., & Kjervik, D. (2008). Therapeutic jurisprudence: A theoretical model for research with adolescent psychiatric mental health populations. *Journal of Nursing Law*, 12, 54-59.
- Roberts, D. (2003). Privacy and confidentiality: The health insurance portability and accountability act in critical care nursing. *AACN Clinical Issues*, 14, 302-309.
- Roe v. Wade*. (1973). 410 U.S. 113; 93 S.Ct. 705; 35 L.Ed.2d 147.
- Ryan, G., & Bernard, H. (2000). Data management and analysis methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 769-802). Thousand Oaks, CA: Sage.
- Rylance, G. (1999). Privacy, dignity, and confidentiality: Interview study with structured questionnaire. *BMJ*, 318, 301.
- Safer v. Pack*. (1996). 291 N.J.Super. 619, 677 A.2d 1188.

- Sandelowski, M. (1995). Qualitative analysis: What it is and how to begin. *Research in Nursing & Health*, 18, 371-375. doi: 10.1002/nur.4770180411
- Schma, W. (2000). *Therapeutic Jurisprudence: Knowledge and Information Services*. The National Center for State Courts. Retrieved from www.ncsconline.org/wc/publications/kis_prosol_trends99-00_pub.pdf.
- Schma, W., Kjervik, D., Petrucci, C., & Scott, C. (2005). Therapeutic jurisprudence: Using the law to improve the public's health. *Journal of Nursing Law*, 33(4), 59-63.
- Security of Health Data*. (1983). N.C.G.S. §130A-374.
- Slutsman, J., Kass, N., McGready, J., & Wynia, M. (2005). Health information, the HIPAA privacy rule and health care: What do physicians think? *Health Affairs*, 24, 832-842. doi: 10.1377/hlthaff.24.3.832
- Smith, S. P. (2000). Are you protecting your patient's confidentiality? *Nursing Economic\$,* 18, 294-297, 319.
- Snider, M. J., & Hood, K. M. (2001). Confidentiality: Keeping secrets. *Journal of Professional Nursing*, 17(5), 213-214. doi:10.1053/jpnu.2001.26302
- Spannagel, C., Glaser-Zikuda, M., & Schroeder, U. (2005). Application of qualitative content analysis in user-program interaction research. *Forum: Qualitative Social Research*, 6(2), Article 29. Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/469/1005>
- Tarasoff v. Regents of University of California*. (1976). 17 Cal.3d 425
- The Nurse Practice Act*. (2009). N.C.G.S. §§ 90-171.19-47.
- The Privacy Act of 1974*. (1974). 5 U.S.C. § 552a.
- The Public Welfare Administrative Requirements*. (2000). 45 C.F.R. § 162.
- The Public Welfare General Administrative Requirements*. (2000). 45 C.F.R. § 160.
- The Public Welfare, Security and Privacy*. (2000). 45 C.F.R. § 164.
- Trueman, I. (2000). Can patients' relatives justify colluding with healthcare staff? *European Journal of Palliative Care*, 7(6), 213-217.
- Unprofessional Conduct*. (2009). F.A.C. 64B9-8.005 (7).
- Uses and Disclosures for Which an Authorization or Opportunity to Agree or Object is Not Required*. (2002). 45 C.F.R. 164.512.

Uses and Disclosures of Protected Health Information: General Rules. (2002). 45 C.F.R. § 164.502.

Uses and Disclosures Requiring an Opportunity for the Individual to Agree or to Object. (2002). 45 C.F.R. 164.510.

Uses and Disclosures to Carry Out Treatment, Payment, or Health Care Operations. (2002). 45 C.F.R. § 164.505.

Wagner, N., & Ronen, I. (1996). Ethical dilemmas experienced by hospital and community nurses: An Israeli survey. *Nursing Ethics*, 3, 293-304. doi: 10.1177/096973309600300403

Warren, S., & Brandeis, L. (1890). The right to privacy. *Harvard Law Review*, IV (5), 193-220.

Wexler, D. B. (1990). Patients, therapists, and third parties: The victimological virtues of Tarasoff. In D. B. Wexler, *Therapeutic jurisprudence: The law as a therapeutic agent* (pp. 201-235). Durham, NC: Carolina Academic Press.

Wexler, D. B. (1991a). An introduction to therapeutic jurisprudence. In D. B. Wexler & B. J. Winick (Eds.), *Essays in therapeutic jurisprudence* (pp. 17-38). Durham, NC: Carolina Academic Press.

Wexler, D. B. (1991b). Putting mental health into mental health law: Therapeutic jurisprudence. In D. B. Wexler & B. J. Winick (Eds.), *Essays in therapeutic jurisprudence* (pp. 3-16). Durham, NC: Carolina Academic Press.

Wexler, D. B. (1996). Therapeutic jurisprudence and changing conceptions of legal scholarship. In *Therapeutic jurisprudence: The law as a therapeutic agent* (pp. 597-610). Durham, NC: Carolina Academic Press.

Wexler, D. B. (1999). *Therapeutic jurisprudence: An overview*. Retrieved from <http://www.law.arizona.edu/depts/upr-intj/>

Wexler, D. B., & Winick, B. (1991a). Introduction. In D. B. Wexler & B. J. Winick (Eds.), *Essays in therapeutic jurisprudence* (pp. ix-xiv). Durham, NC: Carolina Academic Press.

Wexler, D. B., & Winick, B. (1991b). Therapeutic jurisprudence as a new research tool. In D. B. Wexler & B. J. Winick (Eds.), *Essays in therapeutic jurisprudence* (pp. 303-320). Durham, NC: Carolina Academic Press.

Wexler, D. B., & Winick, B. J. (1992). The potential of therapeutic jurisprudence: A new approach to psychology and the law. In James Ogloff (Ed.), *Law and psychology: The broadening of the discipline* (pp. 211-239). Durham, NC: Carolina Academic Press.

- Whetten-Goldstein, K., Nguyen, T. Q., & Sugarman, J. (2001). So much for keeping secrets: The importance of considering patients' perspectives on maintaining confidentiality. *AIDS Care*, 13, 457-466. doi: 10.1080/09540120120057987
- Winick, B. J. (1997). The jurisprudence of therapeutic jurisprudence. *Psychology, Public Policy, and Law*, 3, 184-206. Reprinted from 1996, *Law in a therapeutic key: Developments in therapeutic jurisprudence* (pp. 645-668). Durham, NC: Carolina Academic Press.
- Winick, B. J., & Wexler, D. B. (2003). Therapeutic jurisprudence as a theoretical foundation for these new judicial approaches. In B. J. Winick & D. B. Wexler (Eds.), *Judging in a therapeutic key: Therapeutic jurisprudence and the courts* (pp. 7-10). Durham, NC: Carolina Academic Press.
- Woods, S., Beaver, K., & Luker, K. (2000). Users' views of palliative care services: Ethical implications. *Nursing Ethics*, 7(4), 314-327.
- Wrongful Disclosure of Individually Identifiable Health Information*. (1996). 42 U.S.C. § 1320d-6.
- Yang, J., & Kombarakaran, F. (2006). A practitioner's response to the new health privacy regulations. *Health & Social Work*, 31, 129-136.