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“BEING CERTAIN”: MORAL DISTRESS IN CRITICAL CARE NURSES

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing at Virginia Commonwealth University

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Abstract

“BEING CERTAIN”: MORAL DISTRESS IN CRITICAL CARE NURSES

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Moral distress is the suffering that occurs when one is unable to do what that individual believes to be the right thing, based on personal values and world view. The purpose of this qualitative study was to explore the experience and meaning of becoming certain of the right course of action in the context of moral distress. The study design was an interpretative approach incorporated with narrative analysis as developed by Clandinin and Connelly. A maximum variation sample of 10 critical care nurses from three medical centers included diversity of gender, ethnicity, age, years of practice, and education. Face to face interviews were audio recorded and transcribed verbatim. Analysis focused on constructing and reconstructing a shared narrative. Participants “recognized” or “knew” the right action as they considered the situation within its context and their own personal context, and they determined what was right, from their own perspective of “doing good” and avoiding a sense of failure that would come from “not

doing good". Results highlighted an absence of resources to provide an alternate to individual determinations of the "right course of action", creating an environment, in which participants had to rely on what they knew for themselves. Moral certitude, an unintended consequence, resulted from a lack of alternate knowing. Recommendations for practice and future research were addressed.

Chapter 1 Introduction

The term “moral distress” was coined in 1984 and defined as a negative experience, in which a nurse finds he/she knows the right action to take, but is unable to carry out that right action due to institutional barriers (Jameton, 1984; 1993). Failure to alleviate moral distress can impact patient care, lead to job stress and staff turnover, and cause some nurses to leave the profession (Caitlin et al., 2008; Corley, 1995; Fry, Harvey, Hurley, & Foley, 2002; Gunther and Thomas, 2006; Gutierrez, 2005; Hamric & Blackhall, 2007; Millette, 1994; Pendry, 2007).

Moral distress was proposed as a nursing diagnosis in 2005 and accepted at the North American Nursing Diagnosis Association, Nursing Interventions Classification, and Nursing Outcomes Classification Conference (NNN Conference) in Philadelphia in March, 2006 (Scroggins, 2006). Although moral distress is not limited to nurses, it is thought to be especially prevalent in nurses because of the practice hierarchy that positions nurses in the middle, between health care institutions, patients and families, and physicians, creating the opportunity for moral tension (Englehardt, 1985; Hamric, 2001). Others have offered that because of the close proximity of nurses to patients, nurses are more likely to develop moral distress than are members of other health professions (Peter & Liaschenko, 2004). Another interpretation of moral distress moved it beyond an experience to “...a negative state of psychological disequilibrium” (Wilkinson, 1987, p.16). Two forms of moral distress have been distinguished: initial and reactive (Jameton, 1993). In addition, long after the morally distressing situation has ended,

negative effects of moral distress can linger in what Webster and Baylis termed moral residue (2000). The American Association of Critical Care Nurses (AACN) Public Policy Position Statement: Moral Distress, defined moral distress as occurring when “you know the ethically appropriate action to take, but are unable to act upon it and you act in a manner contrary to your personal and professional values, which undermines your integrity and authenticity” (2008, p.1). Equally present in the literature, were citations of Corley’s work that identified situations that can lead to moral distress, potential consequences for the individual nurse, and the negative impact on the profession as a whole (Corley, 1995; Corley, 2002; Corley, Elswick, Gorman, & Clor, 2001; Corley, Minick, Elswick, & Jacobs, 2005). The only published literature that did not cite Corley were the six articles that preceded her work (Fenton, 1988; Jameton, 1984; Jameton, 1993; Millette, 1994; Wilkinson, 1987; and Wilkinson, 1989). One situation found throughout the literature and described as causing moral distress, involved nurses delivering care that the nurse identified as not in the patient’s best interest. This was one possible avenue for the nurse to conclude that he or she knew “the right action to take,” however how the nurse reached this conclusion has not been systemically examined. Since “knowing the right action to take” can be a precursor to the experience of moral distress, a better understanding of its construction is needed.

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Chapter 2
(Manuscript 1)

Assumptions, Certitude, and Moral Distress

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Assumptions, moral certitude, and moral distress

Moral distress is commonly defined in the nursing literature as knowing the right action to take while not able to translate that knowledge in to action because of internal or external barriers.¹⁻² After critical review of the unintended consequences of assumptions embedded in this definition, a revised definition of moral distress is proposed, one which incorporates the possibility of transforming that which is experienced as distressing into that which could be liberating. The proposed revised definition is based on an analysis of the published literature, which reveals predominant views on nurse moral distress and illustrates the (unintended) consequences of those views. Making explicit the assumptions embedded in the published literature may contribute to the development of a new framework for considering the concept of nurse moral distress.

Engaging in critical inquiry concerned with assumptions calls for a declaration of the underlying assumptions on which the project is based and more specifically of the investigator. My first assumption is that assumptions can be identified. Next, we assume that the literature describing the practice of nursing is an accurate reflection of that practice. Third, we assume that generalizations made about nurses and published in the literature become a perpetuating force on nursing identity, “who I am supposed to be, how am I supposed to act, how am I supposed to respond” as nurse.

Finally, we make the assumption that moral certitude plays a role in the development of some situations of moral distress. As defined by Vaiani³, moral certitude is a position in which one decides the moral or “right” course of action and anyone who disagrees with that view is wrong.

Context

As an ethics consultant of 20 plus years in a large teaching facility, the first author has noticed that not all ethics consultations in which she has been involved, are requested for help in identifying the ethically appropriate actions in the face of an ethical dilemma: choosing between two equally hard choices, weighing the benefits and burdens of each, the traditional “ethics consult,” as described by the late John Fletcher,⁴ a pioneer in biomedical ethics. Some of the consults seem to involve a position of moral certitude rather than requests for help with resolving an ethical dilemma (“what is the ethical thing to do?”). The person making the request claims to know the “right” or “correct” course of action and seeks assistance in identifying strategies to achieve what she or he has deemed to be morally right. It is often unclear how the determination of the “right” action was made. This type of consult is especially challenging as participants, whether staff or family members, tend to be unwilling to consider the possibility of other perspectives or options.

These personal observations and reflections led to a discussion of these experiences with five ethics colleagues from other health care institutions, including federal medical centers, for-profit systems, non-profit systems, and university medical centers. Each of the colleagues shared similar situations to what that presented above and encouraged proceeding with the desire to explore moral certitude as a possible precursor to moral distress, as well as presenting a new framework for considering moral distress.

The purpose of this paper is to systematically and critically evaluate published literature on nurse moral distress, in order to identify and examine assumptions that underlie the construction of the concept of moral distress in nurses. Consequences of the assumptions will be examined, leading to a proposed new framework for considering nurse “moral distress”. Such a

framework could offer new options to those who confront ethically challenging situations. With nurse turnover attributed to moral distress as high as 15% this is an important investigation to undertake.⁵

Assumptions underlying the construction of nurse moral distress

Since 1984, when Jameton^{1,2} coined the term “moral distress”, there has been discussion in the literature and elaboration of the assertion that nurses can experience moral distress when they encounter barriers preventing them from taking what they believe to be the right or morally correct action. Failure to alleviate moral distress has been linked to adverse influences on patient care, job stress and staff turnover, and departure of some nurses from the profession.⁶⁻¹⁴ The financial drain of job turnover in nurses, as discussed by Pendry¹⁵ has been documented at roughly \$46,000 and \$64,000 for medical-surgical nurses and critical care nurses respectively with additional costs of overtime increasing those amounts to as much as \$92,000 and \$145,000.

Definitions have established and reified moral distress as a fact of experience, giving rise to national policy statements on the concept. The American Association of Critical Care Nurses (AACN) Public Policy Position Statement: Moral Distress defined moral distress as an experience occurring when “you know the ethically appropriate action to take, but are unable to act upon it and you act in a manner contrary to your personal and professional values, which undermines your integrity and authenticity.”^{16(p1)} Another interpretation moved moral distress beyond an experience to “...a negative state of psychological disequilibrium.”^{17(p16)} Two forms of moral distress have been constructed and distinguished: (1) initial, the negative feelings the nurse experiences and (2) reactive, the distress the nurse experiences when not acting on what the nurse “knows” to be right.² In addition, Webster and Baylis¹⁸ coined the term “moral residue” to describe the lingering negative effects of moral distress.

Further, moral distress has been described in the health care arena as a phenomenon that is not limited to nurses and can be experienced by anyone who faces barriers to doing the right thing.¹⁹⁻²⁴ In addition, in 2005,²⁵ moral distress was proposed as a nursing diagnosis for patients and accepted at the North American Nursing Diagnosis Association (NANDA), Nursing Interventions Classification, and Nursing Outcomes Classification Conference (NNN Conference) in Philadelphia in March, 2006.²⁶ As a nursing diagnosis, moral distress takes on a privileged status as a diagnosable phenomenon, for which defining characteristics and recommended interventions have been determined. In the NANDA taxonomy, moral distress refers to the distress experienced by patients or their surrogates when constrained and unable to proceed with their moral choice.

Although the experience termed “moral distress” is not limited to nurses, Engelhardt²⁷ and Hamric²⁸ have claimed it is prevalent in nurses because of the practice hierarchy that positions nurses in the middle of health care institutions, physicians, and patients and families, creating the opportunity for moral tension and the experience of moral distress. The notion of practice hierarchy incorporates the assumption that the nurse will encounter institutional barriers to action. Other authors have suggested that because of the close proximity of nurses to patients, nurses are more likely to develop moral distress than other disciplines.²⁹ Thus, the construction of moral distress as an almost inevitable part of nursing practice becomes evident.

All of the available moral distress literature has referred to Jameton’s¹ definition of moral distress as knowing the right action to take while not able to translate that knowledge in to action or cited a secondary source that credited Jameton^{1,2} with the definition of moral distress. One cause of moral distress frequently noted in the literature involved situations in which a nurse delivered care to a critically ill patient who lacked decision making capacity, and that care was

deemed by the nurse as not in the patient's best interest.^{5-7,9,22,30-32} Deeming care as not in the best interest of a patient, without offering an understanding of how "in the best interest" was known seemed to be based on the assumption that the nurse can have indisputable knowledge of the morally correct action to take.

A variation from Jameton's¹⁻² definition of knowing the right action and being unable to implement that right action, was evident only in Hanna's¹² exploration of moral distress in nurses' experiences of caring for women undergoing elective termination of pregnancy through abortion. Hanna offered that the experience of moral distress and its cause may depend on the perception of harm to what the nurse values as good, rather than knowing the right action to take and the inability to make that action happen.

Within the moral distress literature, the experience of nurse moral distress appears to be justified by the assumption that, "Nurses are particularly vulnerable to moral distress because of the nature of nursing as a moral endeavor...."^{33(p145)} Nursing is indeed a moral endeavor with moral obligations to those who seek nursing care as outlined in the American Nurses Association Code of Ethics for Nurses.³⁴ In reading the quote above, it is not clear to me how nursing as a moral endeavor increases a nurse's vulnerability to moral distress. It seems to us that the authors presume that nursing is more of a moral endeavor than other professions and therefore nurses are more vulnerable to moral distress. Another assertion found in nurse moral distress literature, identified nurses being at greater risk of moral distress because of the tendency of nurses towards "...agreeableness", a personality trait that included compassion, consideration, and cooperativeness, qualities considered desirable in nurses and used as a proxy measure for caring.^{35(p437)} It is unclear to us, how the author equates agreeableness with compassion as a proxy for caring. We argue that there is another plausible conclusion to that drawn by the author.

Sometimes the unspoken behind “nurses care” is that “doctors cure” or that the caring of nurses is superior to the “caring” of other health care professionals because Nurses “know this patient”. Nursing’s compassionate care also includes the domain of critical thinking that may lead to disagreement rather than passive agreement.

Two additional assumptions we identified within the literature include first, that a nurse knows what is best for a patient, particularly when that patient is critically ill and lacks decision making capacity. And second, when that nurse is unable to proceed with what the nurse “knows” is best, moral distress is an understandable consequence. Corley and colleagues⁵ developed a scale to measure moral distress. In the scale, the authors identified a number of items under the category of “not in patient’s best interest.” Examples included: (1) following a family’s wishes when the nurse disagrees, (2) medical orders for “unnecessary” tests, (3) treatments that prolong dying, and (4) “unnecessary” tests on a terminally ill patient. I question whether assumptions have been made about what is “unnecessary” or that a treatment is life-prolonging for a particular patient based on what that nurse would want for him or herself based on her own experiences, rather than what the patient values and then desires. The Moral Distress Scale, or modifications of it, has been used in a number of studies found in the literature. Each study contained examples of nurse moral distress caused by situations that health care professionals would likely consider “not in the best interest of a patient.”^{11,23-24,31-33,36-38} Negative feelings, if not anger and outrage, could be experienced in response to each of the “not in patient’s best interest” examples the authors presented. Each of us views situations through a world lens that includes individual experiences, beliefs, and values. Assumptions such as “patients have a right to a peaceful death” or “actions that are life-prolonging when death is inevitable are undesirable” and “the time and circumstances of impending death can be known with certainty” can lead the

nurse to know the described situation is not something she would desire for herself. To make the leap that the situation is not right for another individual without first exploring that person's wishes makes assumptions that the patient's values and beliefs are the same as the nurse's.

Moral short sightedness can occur if nurses assume that their world view is "right" and fail to appreciate the world view and resulting decisions of family members who have made decisions for their loved ones. Certainly nurses can disagree with a family's decisions, the necessity of tests, or perceived goals of treatments. In deeming a test as unnecessary or a treatment as prolonging death and dying for another individual, the assumption seems to be that the nurse providing care is right about the situation at hand and those who think differently are wrong. This scenario calls in to question whether we as nurses can discern with absolute certainty that we are right in a particular case, especially when the situation involves decisions about a person in our care.

The moral distress literature fails to include the possibility that we cannot discern with absolute certainty that we are right. When we think about "being right", I think about statistical significance in randomized controlled trials (RCT), the gold standard of experimental research designs. In quantitative research there is no absolute certainty, only probabilities that results were not due to chance.³⁹⁻⁴¹ It would be inappropriate to suggest that a quantitative concept such as statistical significance in RCT could be compared with the social and qualitative concept of moral distress. Our point in including the discussion of this quantitative concept is to remind ourselves and the reader that being "right" or "certain" may generate a sense of moral certitude. Even in situations that we presume can lead us to knowing what is true, we don't end up knowing what is true. Arriving at "the true or right answer" is not easy.

Claims that nurses know what is right and what is best for someone else are found in the moral distress literature, with treatments viewed as “not in the best interests of patients” sometimes labeled as futile.^{32,42-45} Defining futility can be challenging and in the moral distress literature is virtually non-existent. Definitions of futility have been proposed and can be found in medical journals, especially in situations involving critical care, although consensus has not been reached. Such definitions include treatments that have not worked in 100 similar situations or treatments that serve only to prolong life.⁴⁶⁻⁴⁸ Within the moral distress literature it is unclear how a specific nurse decided a treatment was futile for a specific patient. Without consensus of a definition of futility and within a specific context, the meaning is open to interpretation. What one individual thinks is futile may disagree with how another interprets the same treatment or situation. Use of the word “futility” can create an emotionally charged environment if family members interpret “little to no chance” as actually providing “some chance” when their loved one’s life is hanging in the balance. A nurse may have concluded that “little to no chance” is not in the patient’s best interest, but the family may not yet have arrived at the same conclusion. If the nurse has concluded the situation is “hopeless” and particular treatments are “futile” based on her world view of what is “right”, but the family disagrees and refuses to do things the nurse’s way, the nurse is likely to experience moral distress because she can’t make happen what she “knows to be right”.

Based on Jameton’s¹ definition, facing a situation in which the nurse “knows what is right”, but is unable to act on what she knows to be right can lead to moral distress. It is also presumed in the literature and, even advised that a nurse confronted with morally distressing situations has the right to take action. Those who advocate for taking action suggest conscientious objection, or refusing to participate or follow a particular order, as a possible

solution to morally distressing situations.^{6,12} Conscientious objection is sanctioned by the American Nurses Association³⁴ and the Joint Commission for the Accreditation of Health Care Organizations.⁴⁹ Although an accepted course of action within the literature, conscientious objection can carry negative connotations, such as abandonment of the patient. Conscientious objection can also produce negative images of “draft dodgers” and “war protestors” from an earlier time in our country’s history. These negative images of conscientious objection may be objectionable to some nurses and cause them to look for different solutions to the moral distress being experienced. In the absence of other solutions, nurses may feel hopeless and powerless.⁵⁰

Other solutions to moral distress found in the moral distress literature, have presented the need for moral courage, recommending nurses stand up and speak out for what is right.^{42,51-58} The American Association of Critical Care Nurses⁵⁹ 4 A’s: ask, affirm, assess, and act is a frequently cited reference for standing up and speaking out. *Ask* reminds nurses to review the definition of moral distress and decide if their feelings point to moral distress. *Affirm* instructs nurses to affirm their feelings and identify what aspect of their moral integrity is at stake. *Assess* tells nurses to decide the right course of action. Finally, *Act*, reminds nurses to create and implement an action plan. This would assume that the nurse knows with certainty what is right.

Adding moral reflection to everyday practice

In *The 4 A’s to rise above moral distress*⁵⁹ nurses are encouraged to Ask, Affirm, Assess, and Act. The “4 A’s” help nurses arrive at judgments and actions and as moral agents nurses hope to discern moral “correctness”. Missing from this framework is moral reflection. Without moral reflection, discerning moral correctness may be difficult at best. A nurse who fails to engage in moral reflection may instead be stuck in a position of moral certitude and see only one

possible moral option, the option she chooses, rather than understanding all possible morally “correct” options.

In the moral distress literature, few examples can be found that link moral reflection in nurses and “morally correct” actions.^{3,12,60} The AACN Standards for Establishing and Sustaining Healthy Work Environments,⁶¹ addressed one of its standards for a healthy work environment that included the language “true collaboration” and provided the following critical element, “The healthcare organization ensures unrestricted access to structured forums, such as ethics committees, and makes available the time needed to resolve disputes among all critical participants, including patients, families, and the healthcare team.”^(p4) Assumptions underlying the involvement of ethics resources are that ethics facilitated discussions can assist with the resolution of morally distressing conflicts by providing collaboration between patients and families and members of the health care team, through facilitated conversations, especially when communication has broken down.⁴ Examples of ethics facilitated discussions as possible interventions for moral distress have been included in the literature review of this paper.^{44,62-63} Quantifiable results of the published reports of ethics consultation led discussions are not available since ethics discussions encourage reflection and insight, not a quantifiable answer or outcome. An ethics facilitated discussion can provide the opportunity for all voices to be heard allowing true collaboration. What may have begun as assumptions about what is “right” by an individual, leading to judgments and actions with potential moral distress for all involved in the patient’s care, including family members, can instead evolve in to moral reflection and an understanding of differences in values of and choices by those who participate in the facilitated conversation. Without moral reflection, moral certitude may prevail, stifling the openness to and understanding of all possible morally appropriate actions. An underlying assumption here is that

moral certitude is non-productive and limits the exploration of choices in situations when an individual has judged a situation to be morally reprehensible or morally outrageous. Another assumption is that one way to identify and de-emphasize moral certitude is through a facilitated ethics discussion.

Ethical framework

It may be helpful to imagine a continuum of different ways of thinking about difficult situations such as what care is best or right for a critically ill person without decision-making capacity. The continuum presented for this paper places moral certitude at one end and moral reflection or contemplation at the other. When experiencing moral certitude, I am convinced of the correctness of my view. The intent is to do what I see as the “right thing” and to fix problems, assuming that the situation is “a problem” and “it can be fixed”. The moral certitude end of the continuum can be thought of as the “doing” or “fixing” end. Historically and currently, nurses have received praise for doing and fixing. The nurse who learns the most skills, is most proficient at those skills, and can “do” the most the fastest is likely to be viewed as a leader in that area of care, the go-to person for complex care. With certitude, “I know” what is right or best & the “fix” can only occur “my way”. There is a strong attachment to one perspective with moral certitude, as discussed earlier.³ At this extreme, communication and therefore relationships can be interrupted. Options and choices are limited. The views of others are diminished, demeaned, and even dismissed, as are the others in general who are involved. If a nurse has little or no support from other clinicians for the “I know” what is right, the situation can become isolating and alienating for that nurse.

At the contemplating or reflecting end of the continuum, the intent is to be open to various perspectives. Many views are possible about how important issues get resolved including

options and processes for resolution, although some options are preferable or more feasible in a given context. The contemplative approach is seeking and curious as well as appreciative, open, receptive, and respectful. An important teaching of Buddhism is to acknowledge that I know only that I do not know.⁶⁴ A contemplative nurse may be viewed by colleagues as wishy-washy, non-doing, ineffective and inefficient. Time is wasted on inaction, “doing nothing”, as no quick fix is found. For those who lean towards doing and fixing, there may be increased discomfort in not “fixing” a situation.

When faced with distressing situations, interpreting the situation through “I know” what is right, wanting to “fix the problem” and finding that the nurse cannot fix it may lead to moral distress. Lessening the strong attachment to what “I know” is right and increasing the openness to various perspectives, introduces humility and may reduce the precursor to moral distress.

Moral distress has been socially constructed to convey the concept, that a nurse knows what is right, but does not or cannot carry out the right action. Knowing what is right is an unquestioned assumption. Individuals view situations through their world lens, operating from what they know, what they have been taught, their experiences, and their values, including institutional policies and professional codes. When nurses experience this state of “knowing” what is right in the face of perceived barriers that prevent taking the “right” action, a flag should be raised or an alarm sounded. Instead of assuming what is right for another person, let each nurse find the moral courage to morally reflect and consider other possibilities before any action is taken. Instead of the currently accepted definition of moral distress that includes assumptions outlined above, a new definition building on the work of Hanna¹² may be prudent. The following is offered: Moral distress is the experience of being asked or ordered and expected to carry out an action that conflicts with what that nurse believes (not knows) to be right, based on that

nurse's values for herself, and the perception that the nurse is powerless to act on his or her presumption of what is "right". By changing the "knowing what is right" to "what I believe to be right," the door is opened to the possibility that the nurse does not know, that the nurse is wrong, that what is occurring is a situation that conflicts with the nurse's moral integrity, a conflict between the nurse's values and the values of others. By adding the "I believe," the dogma of doing it the nurse's way, of being right is diminished and moves the nurse away from the arrogance of moral certitude. What the nurse "believes", instead of "knows" becomes one possibility rather than the only possibility. Once the dogma of being right is removed, other voices can be heard, allowing other values to enter in to the ethical conversation.

In the above proposed ethical framework, assumptions are acknowledged. First, the assumptions are made that an ethical framework and a revised definition of moral distress are needed. Additionally, an assumption is made that by being aware of moral certitude and its influence on our thoughts and actions change is possible.

In summary, this paper evaluated published nurse moral distress literature to identify and critically examine assumptions that underlie "knowing what is right," particularly as the assumptions relate to care of critically ill individuals without decision making capacity. An ethical framework was presented and a call for nurses to emphasize moral reflection instead of making assumptions was made. Finally, new language for the definition of moral distress was proposed, changing the wording from "I know" to "I believe." By implementing moral reflection and revising the definition of moral distress, the nurse's assumptions may become visible, moral certitude may be eliminated, and moral distress in some situations may decrease.

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Chapter 3
(Manuscript 2: Study Findings)

“Being Certain”: Moral Distress in Critical Care Nurses

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“Being certain”: Moral distress in critical care nurses

Moral distress was identified by Jameton (1984, 1993) as a negative experience, in which a nurse finds he/she knows the right action to take, but is unable to carry out that right action due to internal or external barriers. The definition of moral distress has been further refined to emphasize the importance of individual values and world view (Baxter & Gray, 2012), to focus on the suffering that occurs when one believes the right action to take is known, based on that individual's values and world view, and that individual is unable to make the perceived right action occur. As a phenomenon, moral distress can be experienced by anyone who faces barriers to doing the right thing (Hamric, Davis, & Childress, 2006; Lee & Dupree, 2008; Range & Rotherham, 2010). Failure to alleviate moral distress in nurses is credited with impacting patient care, leading to job stress and staff turnover as high as 15%, with some nurses leaving the profession (Caitlin et al., 2008; Corley, 1995; Corley, Elswick, Gorman, & Clor, 2001; Fry, Harvey, Hurley, & Foley, 2002; Gunther & Thomas, 2006; Gutierrez, 2005; Hamric & Blackhall, 2007; Millette, 1994; Pendry, 2007). There has been no published exploration, of being certain of “the right action to take,” as a possible precursor to moral distress. Thus, an interpretive study design was used to develop an understanding of the experience of being certain of “the right action to take” within the context of nurses' professional experiences of moral distress.

The research study addressed the question, among critical care nurses (RN) who have experienced moral distress in the clinical practice setting, what was the experience and meaning of knowing the right course of action? Specifically, I wanted to understand context, characteristics, and dimensions of the participants' situated reality of “knowing the right action to take.”

Methods

I employed an interpretive research design using narrative inquiry, as outlined by Clandinin and Connelly (2000) and focused on the construction of being certain of “the right action to take” in the context of participants’ moral distress experiences. Narrative inquiry challenges previously “accepted inquiry and representation assumptions” (Clandinin & Connelly, 2000, p.184) and focuses on understanding individual experiences as lived and retold stories. As Connelly and Clandinin expressed, “...humans are storytelling organisms who, individually and socially lead storied lives. The study of narrative, therefore, is the study of the ways humans experience the world” (1990, p.2). In narrative inquiry, the goal is not to find “truth”, but instead, to understand the individual’s experience.

Sampling

A maximum variation sampling approach was used to explore the perspectives of nurses with diverse ages, years of clinical practice, nursing education, gender, and ethnicity. Inclusion criteria were: current employment as a registered nurse (RN) in an inpatient critical care setting, either in an academic or community hospital setting; ability to speak and understand the English language; and self identified as having experienced moral distress as a result of professional work experiences, based on Jameton’s definition of moral distress (1984, 1993). I limited the sample to registered nurses from inpatient critical care settings in order to establish consistency with the existing published research on nurse moral distress.

Following IRB approval, formal permission was obtained from the local area chapters of American Association of Critical Care Nurses (AACN) and other professional nurse organizations, including Filipino Nurses Association, Black Nurses Association, and Hispanic Nurses Association, to distribute information about the study and to solicit participants for the

study. Solicitation occurred via list-serves and professional contacts from March to September, 2012, within one geographical area of the mid-Atlantic region of the United States. The information flyer provided instructions for interested RNs to contact me directly, by phone, e-mail, or in person. When contacted, I explained the purpose of the study, answered any questions, and assessed whether the interested nurse met the inclusion criteria and would expand the variation of the sample. Once an individual who met the inclusion criteria and who expanded the variation of the sample agreed to participate, I scheduled an interview and obtained the informed consent. I conducted the interviews in a setting of the participant's choosing. Most often, interview sites were private offices or conference rooms in the participant's work location. One interview was conducted in a participant's home. Confidentiality was maintained at all times throughout the study.

Data Generation

I used an iterative approach to qualitative data generation and analysis to allow ongoing participant selection, interview, and analysis of data to facilitate maximum variation sampling. I audio-taped the individual semi-structured interviews and then transcribed them verbatim into text format. Transcription was initiated within 24 hours of the interview and completed within 24 to 72 hours.

During the 60 to 90-minute semi-structured face-to-face interviews, I asked participants to share thoughts, feelings, and reflections about a morally distressing experience in the work setting. Interview questions included: 1) Tell me about a situation in which you experienced moral distress. 2) Where and when in your career did this occur? 3) Tell me more about being certain you knew the "right thing" to do in this situation. 4) Tell me about the barriers or obstacles to carrying out the "right action" in this situation. 5) Is there anything else you'd like to

tell me? Additional questions were posed to explore the context and meaning of the comments verbalized by the participant. During the interview, I made brief and inconspicuous notes to identify key concepts or observations regarding behaviors, facial expressions, and expression of emotions. In addition, I recorded notes immediately after the interview to explicate behavior, to note impressions, or to place data in context. I completed field notes to assist me with accurately interpreting specific events and recounting the interview, as well as placing my relationship and past experiences within the narrative inquiry. Permission was obtained from each participant for future contact to clarify information from the interview session. This additional contact was not needed and therefore did not occur. I sent a follow-up email message thanking each participant for participating and encouraging each participant to contact me for additional thoughts or questions. I neither made nor received further contact with any participant.

Individual participant demographic data forms were completed by me to obtain information describing the total study sample. Additional study data consisted of my notes and personal reflective journaling that included personal assumptions and biases, reflections on personal experiences and insights, and notes regarding methods and decisions. Use of the personal reflective journal heightened my attentiveness to self and others, enhanced understanding and interpretation, and stands as a record of the ways in which the study design was implemented (Clandinin & Connelly, 2000). These multiple sources of data allowed me to explore and clarify underlying assumptions held by myself and the study participants, as revealed through their stories.

Data Analysis Process

Quantitative demographic data were summarized to describe characteristics of the participants and to describe the outcomes of the maximum variation sampling approach.

Transcribed interview texts, my notes taken during the interview, and my personal reflection journal served as the qualitative data for analysis.

Qualitative data were analyzed according to the narrative analysis methods and procedures outlined by Clandinin and Connelly (2000). Their conceptual framework for narrative inquiry included attention to temporality, sociality, and place, and specifically addressed “...collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus” (Clandinin and Connelly, 2000, p.20). As part of the analysis, I acknowledged that all of the stories, the participants’ as well mine, were retold stories with a past, present and future, that changed over time and within the context, in which the stories were shared with others. The narratives were socially and geographically situated and included the relationship between myself and participants. I was present in the stories as both a listener/researcher and as a nurse who had experienced similar events and feelings. Primarily, the events occurred within critical care units and the retelling of those events by participants took place within quiet and private spaces selected by the participant.

Results

A total of 13 potential participants contacted me about the study. One of the 13 declined to participate after learning there was no monetary compensation. Two potential participants failed to return repeated electronic mail and phone messages over the six month period of recruitment. All those who contacted me and agreed to participate were included in the study.

The maximum variation sample included ten RNs from three health care institutions, representing eight adult critical care units. Represented ethnicities included Caucasian, African American, Hispanic, and Asian Pacific Islander. Age ranged from 25 to 62 years (mean of 42 years). Years of nursing practice ranged from 1.5 to 33 years (mean of 14 years). The sample

included 40% white females. Males made up 30% of the sample. Characteristics of participants are summarized in Table 1. The critical care units were represented in the summary table as either medical or surgical to protect participant confidentiality.

Study results are presented to answer the research question, among critical care nurses, how did participants become certain of the right course of action and what meaning did “being certain” have for the participant? The question was answered by using the data sets of participant quotations from participants’ stories, my recalled experiences related to moral distress as a new graduate, and my reflections on both. The ways in which the experience of “knowing the right action to take” in morally distressing situations was contextually mediated was also examined. Aspects of the context included the participants’ backgrounds and the specific situation in which they experienced “knowing the right action to take” as related to moral distress.

“Knowing the Right Action to Take”

Within and across participant narratives as well as in my own narrative, a persistent and unifying narrative was present, a grand narrative of an internalized imperative to “do good” and to avoid its opposite, not “doing good,” which represented failure as a nurse. Examples of participant quotes of “doing good” included: “...we didn’t really do that person any good”, or “...are we helping them or are we hurting them?”, or “what good did we do?”, and “we...take good care of our patients, do the right thing.” The following quotes illustrated wanting to avoid not “doing good,”

I don’t think they ever got out of the hospital...I think they got off our unit...came back and died...we didn’t really do that person any good...What is morally right? ...your morals might be a little bit different than mine, so...maybe I am wrong, and maybe we are doing the right thing...given this person’s beliefs, values... but no, no, it’s not, it’s awful...I’m not doing anything good. I’m putting bandaids and I’m extending grief and suffering. I mean I’m the evil. I’m the tool of the surgeons that are doing these awful surgeries to people. And for me...I’m leaving (Participant 1).

...you feel like you're chopping people up...it's cruel to put somebody through that... it's a painful surgery... it's just brutal...it's almost like starvation...I don't think this should be an option for them because they could die in the hospital...their manner of death was ...just uncalled for...you feel like you lie a lot...it's a dog's death... I'm [leaving]. I don't want to see people die any more (Participant 6).

Participants “recognized” or “knew” the right action as they considered and decided based on their personal sense of “doing good,” thus avoiding a sense of failure that would come from “not doing good”. Some excerpts that illustrated “doing good” included: “...there's a way to turn things around.” and “We want them to get better.” Not “doing good” involved a general belief that the death of a patient was a failure. Assumptions that participants held about their professional roles were identified and included the following themes: nurses are patient advocates, nurses care, and nurses know the patient. Tensions were made visible through the underlying assumption that nurses “do good,” suggesting that others therefore do not do good or are potentially not as good. For each theme of nurses “doing good” whether being “patient advocate”, “caring”, or “knowing the patient”, there was the implication that others in health care were not patient advocates, did not care to the degree that participants did, and did not know the patient as well as participants did and therefore did not know what was the “right action”. As one participant stated,

... why I do what I'm doing if I'm just causing harm? ...that's not why we got in to nursing. We want them to get better...the family members just don't know when to stop or get to the point where they just can't...the doctor's here for 10 minutes or 5 minutes, but the nurse is here at the bedside 24/7... and they know what's going on, sometimes more than the physicians...the nurse takes over, becomes the patient's advocate (Participant 9).

In addition, if “doing good” did not occur based on what the participant believed was “right”, a sense of failure resulted. For many, “doing good” was exemplified by having the patient leave critical care intact both functionally and cognitively and anything less, especially death, meant failure. As one participant shared, “...you'll get better and go home...there's a way

to turn things around.” The following excerpts demonstrate the grand narrative as well as the mentioned themes:

... feel like you are torturing the patient more than actually helping them... just making it worse...are we helping them or are we hurting them?...you're not really sure where it's going...where it will end...I don't know if I am lying to them...don't know how to advocate for them when you have no idea what they would want and you can't ask them...the ones you want to change are the ones that turn out poorly (Participant 2).

I will advocate for my patients...people know I can be outspoken...we fight...to take good care of our patients, do the right thing... why do I care that much?...why should I ever have to fight that hard against someone who's supposed to be on my side?... I felt entirely alone. I was the only one fighting for this patient...I'm done...I cannot be therapeutic...I'm going to do more harm than good. It's time for me to move on (Participant 4).

Reflections. Attending to Clandinin and Connelly's (2000) narrative framework of temporality, sociality, and place in the above excerpts, I have retold the participants' stories of past critical care unit experiences. The stories included relational aspects between participant and patient/family with the goal of “doing good” through interventions that resulted in patients going home in “healthy” states. My personal narrative regarding past similar experiences as a new graduate in critical care resonated with the stories of participants in this study. Thus, I had a sense of connectedness with participants and their stories. However, participants were not likely to share the relational sense I had of “connection through a shared experience”, since I did not share my experiences with them. “Place” in these stories was the intensive care unit.

Contextual Background for Participant Knowing the Right Thing to do

Contextual background for participant experiences of moral distress included those experiences that preceded moral distress, but that generated a sense of frustration, confusion, or isolation and provided the backdrop, against which moral distress occurred. One aspect of the contextual background included challenges faced by and presented by new graduates working in critical care units. Four participants began their critical care practice as new graduates. The

context of new nurse orientation and its focus on technical skills failed to provide guidance for addressing situations that led to their experiences of moral distress. A second contextual background feature that contributed to the escalation of feelings of distress for all participants was ineffective communication and their inability to improve the systems for communication. Lastly, potential resources to alleviate morally distressing situations were either unknown to or underutilized by participants. Without the proper tools to meet and manage potential morally distressing situations, the participants were left to flounder, creating an environment where each participant was left to his/her own interpretations and assumptions of the “right action to take”, thus potentiating the participant’s moral certainty, a possible precursor to moral distress.

New graduates in critical care units personally faced challenges and presented challenges to others. Four participants began employment in critical care as new graduates and struggled with a perceived lack of support while learning to be nurses in that setting. The following excerpts demonstrate a feeling of isolation and being unprepared for the transition from student nurse to staff nurse as well as being abandoned by the institution where they practiced,

...there is a really big disconnect between nursing school and real life...if I would have been taught in nursing school about these kind of situations...to help me...you have to just live it. I feel like they empower you a lot in nursing school, but when you hit the real world, you don’t feel that same empowerment (Participant 1).

They switched my preceptor after day one... from then on I was in the ICU. ...you have a manual you’re supposed to follow and fill out... no one told me I had to fill it out. They just said here read this. I was bounced between three or four preceptors...never officially told this is your preceptor.... even before I was done...OK, today’s your last day of orientation. You’re going to be on your own tomorrow. I thought I still had two weeks. ...I was calling some of my friends and said, look I can’t take this anymore...she was like, this is your first year, this is how it is, everyone feels the same way (Participant 3).

From another perspective, two participants with 23 and 33 years of practice respectively, shared stories of the impact of new graduates on their units. Their stories shed light on perceived

processes that were inadequate for transitioning new graduates from school to the workplace creating situations that increased the likelihood of failure for the new graduate. Experiencing a sense of failure or perceiving that “doing good” did not occur could result in moral distress.

...some...new nurses...stick around for about a year or two and transfer because they couldn't take the stress...I'm not sure why...what they were lacking or how could we have made it better...all of them did have pretty tough patients...where things didn't go right...I think about the stress... why they left so quickly...I'm not exactly sure why they couldn't stick around and be an ICU nurse for 10 years... (Participant 8).

Another participant described the burden for staff who felt a sole sense of responsibility for the safety of patients who were under the care of a new graduate.

...at one point we had eight [new grads] at the same time.... It was very hard... It burdens the unit, it burdens them. We have one now, comes to work crying...no matter how many resources you give them...you can tell the anxiety... just saying, hi how are you today and the tears will just come and finally I just said this is not for you.... Your patients will see it...I feel unsafe...you might make a mistake and I can't catch it...I have to watch you... With staffing, it's going to be hard for me to watch you. You can't put that on me (Participant 10).

Technical focus of new nurse orientation. Participants, hired in ICU as new graduates, shared experiences of their orientation that focused on technical skills. This focus on the “doing” of nursing conveyed a value system (“doing” is most valued) within that practice setting, mediating against skill development in self-knowing and self-reflection with respect to one's personal value systems and their influence on decision-making.

...this is mean and cruel, but at first when you're getting cases... you're like excited... the scientific part... you want to give these drugs, the blood pressure going down, I'm gonna do this...fun learning experience...you're treating the patient, you're not really thinking about the patient...that first month or two... getting a ton of cases...then when you get good at it...you start noticing other things...like what good did we do?...my first experience with moral distress [was] why are we doing this? I think our unit does a horrible job of orienting new nurses...three preceptors [in three months]... there's so much concern with the tasks and the check offs...the devices...machines... a technical orientation...they hope your skills get organized... they... never breach the why, what do you think...how do you feel, why are we caring for this person...that was never broached at all (Participant 1).

Communication challenges. A number of participants described ineffective communication as contributing to their overall sense of isolation, as it seemed no one was listening. As one participant noted “I fixed my problems on my own...I internalize...you learn sometimes there’s an immovable rock, so best to avoid it...talking about it just makes more problems...it’s never going to change.” Overall, communication was perceived to be for solving immediate (often life or death) problems, without time or commitment to reflection and self-understanding. “...well I just acquiesce. I feel it here [pointing to gut], but I can’t fight the system here. I’m just one nurse...” or similarly, “you have to just put up with it and do what you have to do and not focus on it and not dwell on it.” These communication-related experiences and perceptions appeared to leave participants with a sense of isolation and bleakness.

Isolation in the context of determining the “right” action. In probing for what processes were in place or what resources were available to participants for their morally distressing situations, themes that I developed and made visible are that participants made assumptions that resources were unavailable, did not exist, or were too much trouble to access. In the three represented medical centers, both ethics consultation and ethics committees were available, although no participant verbalized having requested help from institutional ethics resources. As one participant stated, “I have been involved in the ethics committee, um, at another facility, but I have never seen the ethics team here.” Other examples included,

I really don’t feel there is any resources...I mean the ethics committee, if we do, the physicians get mad at you... Seems like years ago we didn’t have to have that extra step. The physician didn’t have to sign off. If we wanted to put in an ethics consult, the committee met, now that’s no more (Participant 6).

...we thought about ethics...the wife didn’t want... even the chaplain.... You look at your resources...for new nurses it’s very hard to find the resources...The problem with [our] ethics committee, it’s organizational ...unless you have a really good case to present to them.... I think there should be ethics staff that goes around and says, what about your dilemma today? ...it just feels like you are going to a board meeting.... You

present and they don't know the patients... it takes away the human emotions...the dignity of people... I wish the ethics committee was a little more visible...like rounding (Participant 10).

In addition, no participant verbalized using their critical care team as a resource, nor did any of the represented critical care units function with interdisciplinary teams. Resources identified by all participants included talking to chaplains, family, and peers, or processing the situation alone. The following quotes are from participants who knew of ethics resources in their medical centers, but did not access them,

...Why are we allowing the surgeon to operate on this patient? Why aren't we saying more to the family members? When you know that the management would give you a political answer...you don't ask questions because you have enough on your plate...there is no handbook... You're just asking people why are we doing this...I would not talk to my manager about any of this as I would be on a fast track for fire, for leaving the unit...bypassing the greater issues of why we take prisoners, why we take drug dealers, why are all these elderly people that shouldn't have to have the surgery or suffer (Participant 1)?

...we do have an ethics consultation...nurses are able to do that...I went along with what was happening. I did express my beliefs. Maybe if I had done an ethics consult...it would have been able to alleviate some of the problems...or the patient's prolonged suffering...we probably don't do enough ethics consults...it seems like extra work...in a fast paced ICU setting you see something going on and you don't like it but something else comes up that trumps it (Participant 5).

Four participants did not mention ethics resources and were not aware of the resource when questioned. The following excerpts illustrate a sense of isolation when these participants were deciding the "right action."

How much of it is making them comfortable and how much of it is actually stopping them from breathing? ...is this euthanasia?...if I hadn't given that much Fentanyl or that much morphine.... I don't know what the clinical limits are...what is right...are we allowed to do that?...we have never had anyone come in and talk about the ethics of what we are doing... it's mostly...having a conversation with peers (Participant 2).

I wish there would be more focus for the nurses...the emotional baggage is something we don't talk about. We're so task oriented ...we have a fall huddle... a safety huddle, a code blue debrief...I wish there was a way or I was savvy enough...to have a huddle when someone dies... we have to change our focus and take care of each other...in the

eight years I've been here... we're moving away from patient centered to task centered... checking boxes and everything... is electronic... documentation focused, we're so worried about litigation... we're taking our eyes off the patient (Participant 7).

Reflections. Again, attending to Clandinin and Connelly's (2000) narrative framework of temporality, sociality, and place, throughout the inquiry and analysis, I maintained a focus on my relationship to the topic of this inquiry as well as to the participants in the study. As I left the first participant's home, following the interview, my consciousness was flooded with memories of my own experience as a new graduate working in critical care. Each of the subsequent participant's stories transported me back in time to when I was 21 years old and very excited to be "chosen" for critical care. I realized that I had made assumptions at that time about being "chosen" because I was better qualified than other new graduates, without thinking about the potential burden being placed on the unit or myself as a new graduate.

I reflected on the landscape of healthcare in 1976. My nursing practice began then, prior to the landmark cases of Karen Ann Quinlan (Kinney, Korein, Panigrahy, Dikkes, & Goode, 1994) and Baby K (Annas, 1994). At that time, there was little societal awareness of the allocation of hemodialysis, based on perceived worthiness (Alexander, 1962). These and other ethical dilemmas were the impetus for national efforts to establish ethics committees to help with the identification and resolution of ethical concerns (Fletcher, Spencer, & Lombardo, 2005). In 1976, neonatal units were new, a mere decade since the first adult critical care units opened. The unit had no chaplains, social workers, or psychologists with whom to discuss moral or ethical issues. I turned to coworkers to discuss moral issues. I felt a connection with participants in turning to coworkers, yet my turning to coworkers was in the absence of today's resources.

In relating my experiences to the participants' experiences during data analysis, I questioned myself and was distracted by why participants did not seem to know or did not utilize

available resources to help resolve their distress. I became aware of my bias that the participants should have known and requested help from the available resources. I further recognized my assumption that if nurses but used available resources, relief from moral distress would be possible. I also assumed that because certain resources were established meant that they were in fact available. From the acknowledgement of these assumptions came my awareness that I too was part of the grand narrative of “doing good;” not from “doing good” at the bedside, however, but from my desire to “do good” as an ethics consultant. I felt, in a sense, that I represented all ethics consultants and thus, had failed these participants. I felt a sense of responsibility for their not knowing or not accessing their ethics resource.

Contextual Perspectives for Participant Experiences of “Knowing the Right Action to Take” as it Related to Moral Distress

Contextual perspective for participant experiences of “knowing the right action to take” as it related to moral distress centered on a series of assumptions. These assumptions included what participants considered quality of life, how healthcare resources are or should be allocated, the intentions of others, allowable care options (including legal aspects of care options) and decisions family members make. Notably, one participant made explicit the influence of culture on her assumptions regarding “right actions.”

Personal perspective on quality of life. A number of participants discussed quality of life and knowing what was right based on what they would want for themselves; that is to enjoy a particular quality of life. An assumption was that what the participant would want or not want, others (e.g. patients) would also not want. The first two excerpts focus on death at home instead of in the critical care unit,

I think we should be giving patients the option of going home to die. Who wants to die in the hospital? No one, if it were me, I would want those last days to be spent with family.

No one under 12 can come in there. I couldn't even see a single one of my grandchildren (Participant 6).

...it's uncomfortable to suction somebody down close to the crina...it has to be horrible... every two hours...we're not their family, they don't recognize our voices... they're cold or they're too....I just see it as... suffering....I'd rather be in my nice warm comfy bed...by myself...than being on a ventilator and cold and not able to express yourself, communicate... we don't know how much they are able to understand, how much they are there or not there, which is how I see suffering...(Participant 9).

The next two excerpts highlight personal preferences to both evaluate the clinical situations of others and inform their decisions regarding “the right thing”,

... they may survive, but...with missing toes and limbs and trachs...their quality of life afterward... did we really save them if they wish they were dead afterwards...I would want people... where they can still walk... breathe on their own...the idea of someone living in a facility, dependent on machines and medications is not much of a life (Participant 2).

... he knew he would never eat Mama's cornbread. I understood what that means, 'cause I love me mama's cornbread...some of these patients looked very, very malformed after they healed and they couldn't eat and they didn't have much pleasure in life... (Participant 8).

Last is a story that describes “knowing the right action” based on an assumption regarding the quality of life of a mother that the participant made from the perspective of her own view of what she would want in similar circumstances. The situation involved wanting to keep a patient alive until a mother returned to her adult child's deathbed, which pushed the participant to an extreme action. The nurse later reflected on and questioned whether she had done the “right thing”.

...I...called the mom...he was a Do Not Resuscitate...vent was already on 100%...adequate pain relief...this is her [only child]... if this was [me], if she came... and saw him already dead...I felt that the mom would just grieve even more... what kind of baggage would I have, would she have to endure, if only I'd stayed...if I can just get her here and have her just see a rhythm on the monitor...I pushed an amp of bicarb... she got there, his blood pressure was nothing and his heart rate was going...and then...he flatlined...I struggle with that situation 'cause I felt like...I had played God.... I asked for forgiveness, Lord I'm sorry for intervening (Participant 7).

Personal knowing of who deserves health care resources. Several participants described “knowing” of who should and should not have received health care resources, based on their personal beliefs or assumptions that resources should not be used for those who they viewed as “undeserving”. Examples of “undeserving” included those who “have let themselves go”, prisoners, or those who were non-compliant with their health care regimen.

...wasting millions of dollars... a repeat drug offender... two valve surgeries... coming in for third... endocarditis... why are we doing this?... this patient is going to ... go right back to using and what's the point? ... why are we wasting our time?... we have prisoners... a child molester... I can understand like petty theft... life hardened criminals... getting these million dollar... surgeries. ... you're hearing... again, just an elderly person and given their co-morbidities... they usually all have the same, diabetes ... and usually these people are just, don't care... I don't know what happened..., but they let themselves go... we had one who, it was awful... came to us from prison, had a heart attack... after surgery we did the hypothermia protocol... four days and finally he died... Why are we, as a society... why is the government, why are we paying for this? Why is this right? Taking resources away from people who actually need it (Participant 1)?

... we have patients that should not have been operated on... we had a patient who had, oh my god, he was noncompliant, he was only in his 40's, but was noncompliant, drug abuser, used to be I think a year before. He got a device, he was HIV positive... but that doesn't disqualify you [from] good resources (Participant 10).

For these participants, strongly held personal beliefs about the right of certain people to health care people to health care resources such as intensive care contributed to a sense of certainty about the “right” thing to do.

Relying on incorrect information. Participants described beliefs or understandings about the legal aspects of decision making which contributed to a sense of certainty about the “right” thing to do. The following excerpts showcased nurse decisions about “right actions” based on incorrect information. Participants described conclusions that were based on inaccurate understandings about the legalities of who could make decisions for a patient, and when and what decisions could be made by those surrogates. Examples included staff incorrectly honoring family requests to overturn patient advance directives. As one participant stated,

...an elderly patient...alert and oriented...[prepared]a Living Will... he did not want to be intubated...did not want...any type of resuscitation measures... the doctors were there, so he had a witness and a DNR/DNI [established]...he [became] unresponsive ...his next of kin ...made him a full code... I saw it as morally distressing because he has his intentions made...and she overrode [them]... [we] were legally bound because she had that decision making ...the law in Virginia... whoever is the Medical Power of Attorney...can overturn a DNR/DNI...make them full code... the law was in favor of the wife (Participant 5).

The following quote illustrates “right actions” based on the assumption that patients automatically lose decision-making capacity once intubated,

...every day he would write this is not what I want. You get to the point, I know this is not what you want, but your wife wanted it for you [patient has capacity for decision making]...this is not what he wants and he’s telling us and he’s writing it, but again the medical power is hers, because he is intubated (Participant 10).

We can get families to make the “right” decision. Participants based “knowing the right action” based on their perspective of what was “right” and assumed families shared the same perspective. Stories were shared that included the perceived need for more family education suggesting that if the family understood the situation better, their decisions about what was “right” would be the same as the participant’s. The excerpt showcases the participant’s assumption that a family member and the participant shared the same beliefs and therefore the family made the “wrong” decision based on not having the right information. Not being able to “get through” to family members, so that they would/could make “right” decisions left participants feeling that they had failed the patient by being unable to get the family to make “the right” decision.

Of course when there’s not a lot that can be done, you do what you can for the patient and hopefully the moral distress won’t be such an issue if the patient and family member are on the same sheet of music.... Sometimes [they]...are never willing to see things as they are and accept it. ...when I see family members...that have made decisions like that...I give them as much information as I can to show them this is what’s going on...and by giving her the information, hopefully she could possibly change, change what decisions she has done (Participant 5).

Cultural influences. Cultural influences are likely to inform the development of an individual's understanding of the "right action to take." However, only one participant provided a specific example of how culture informed her thinking about the "right thing." A nurse with 30 years experience in nursing noted the contrast between her culture and US culture in terms of ways that older adults are treated. Her culturally informed perspective about what was "right" was challenged by approaches she observed in US healthcare.

...still wanted to have surgery [age 80]... a lot of co-morbidities...he's not going to be survivable... We are primarily catholic so our views are so very different...how we treat each other...is all based on our belief and our truth...within the catholic community... we share the same values, so it was easier...I have moral distress with the adult population, because I think they are not given their dignity...for example in [my country] elders are treated with respect and dignity...die at home. That's acceptable. They don't have [surgery] to...live another two months...quality of life is not there...no matter how functional they were before, it's still an 80 year old body so recovery is still hard and somehow the surgeon mentality, it's OK, but to us... it's not right...you kind of get used to it, OK, here's another case, but that doesn't take away your caring, but I think you have stuff like that because it's imposed on you (Participant 10).

Reflections. Returning to Clandinin and Connelly's narrative framework of temporality, sociality, and place, I too had made assumptions as a critical care nurse, about what others would choose for themselves and their family members, what others would consider quality of life. The technology, in 1976, that allowed neonates and children to be sustained until they could go home to loving families did not always lead to happy endings. I had begun to notice what I considered horrific outcomes. After hospitalizations of as many as 18 to 24 months, premies were discharged with necrotizing entero-colitis, broncho-pulmonary dysplasia, intracranial hemorrhage, hydrocephalus, shunts, vents, g-tubes, some with all of it. I made an assumption that their parents would see them as I did, alive but not "normal". My other assumptions included that everyone involved shared my values and beliefs and thus my voice spoke for all, and that no one would want "this" for their child or want a child like this.

Two years later, I was employed as a public health nurse in a rural part of the state. The role included making visits to homes of some of the “graduates” from the neonatal unit where I first practiced. Some were now two and three years old with severe cognitive and functional impairments and still dependent on technology. Some of the mothers had stopped their workplace employment to stay home and provide care to their children. The homes were filled with love, not complaints or regrets. I did not discern any of the bitterness that I had assumed would occur after discharge from the unit. Instead, for many, these children were seen as blessings from a higher power. I was acutely aware that what I had assumed was right was not what someone else would consider. I conceded that I had made assumptions about many of the situations I had judged to be right or wrong from those early days of neonatal intensive care.

My story changed over time within the social context and location that allowed me to gain a different perspective. Participants in this study did not have the benefit of follow-up visits in a home setting after hospital discharge, as I did, to see how the story that was mine was different from the patient’s or family’s. Participants remained in the same “place” and societal milieu, potentially perpetuating retold stories of moral distress.

Summary of results

This interpretive study offered the opportunity to address an omission in the moral distress literature; that is, to examine how participants became certain of the right course of action and what meaning it had for participants in the context of their experiences of moral distress. Participants “recognized” or believed they “knew” the right action as they considered the situation within its context and their own personal context, at that point in time and within the critical care setting, and they determined what was right based on “doing good” and avoiding a sense of failure that would come from “not doing good,” from their own perspective.

Incorporating narrative analysis provided glimpses of a number of assumptions within the individual narratives as well as across participant experiences (see Table 2), including perceived challenges. The maximum variation sample and inclusion criteria offered a shared experience of moral distress across different ethnicities, ages, years of practice, education, and gender, though one unique cultural perspective was addressed. The data illustrated that participants made a number of assumptions about “right actions” and what constituted “doing good” that appeared to contribute to their experiences of moral distress.

Results highlighted an absence of resources to provide or facilitate an understanding of alternate world views, which pushed participants to rely on their individual perspective of what was right or good. Participants tended to see it “my” way leading to moral certitude in that moment of making decisions. Moral certitude became a self preserving tool in the face of isolation, relying on what the individual believed was “right” or “good.” With additional situations that the nurse could not resolve, a negative cycle began. One way knowing with resulting confusion, frustration, anger, isolation, and inevitable distress led some to job resignation. Not knowing a different approach resulted in the nurse responding in the same way to similar situations or to different but still potentially distressing situations with the same frustrating result. The nurse began to expect negative responses. A sense of isolation created an imperative for moral certitude that paradoxically increased the risk for experiencing moral distress, therefore increasing the sense of isolation in a self-perpetuating negative cycle..

Rigor

I was the researcher who facilitated the conduct of the study and analyzed the research data. As a doctoral candidate, my dissertation committee provided input, consultation, feedback, and oversight of the project. I took steps to ensure rigor of both study processes and study

outcomes, based on criteria for what makes a good narrative inquiry (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990). Clandinin and Connelly (2000) described narrative inquiry as fluid, necessitating ongoing reflection or wakefulness. In terms of rigor, they have incorporated plausibility and invitation with previously established criteria including Lincoln and Guba's transferability (1985) and Van Maanen's verisimilitude (1988).

As defined by Connelly and Clandinin (1990), a plausible narrative is one that "rings true" for the reader. Activities they described, and that I used, to increase the likelihood that the findings and outcomes were plausible included: purposeful sampling (iterative), audio-taped interviews, and verbatim transcription. A transparent description of the research steps taken and decisions made are included in this report and are detailed in my reflective journal.

The criteria of invitation is the quality that invites the reader to participate in and engage with the narrative (Connelly & Clandinin, 1990), while transferability (Lincoln & Guba, 1985) is defined as the possibility that readers will be able to reach conclusions about transferring the results and conclusions to related situations. To facilitate invitation and transferability, the sample was clearly described and all findings were illustrated with quotes from participants to provide 'thick' description.

Verisimilitude was defined by Van Maanen (1988) as that which makes the story seem real, with the reader transported into the narrative. Techniques that strengthened verisimilitude included: reflective journal, peer debriefing, and peer review using de-identified data. During data analysis and interpretation phases, peer debriefing was ongoing. Using de-identified data, peer debriefing was conducted by two selected professional nursing colleagues with extensive expertise in nursing or specifically in critical care. Peer debriefing provided the opportunity for on-going response and feedback of data interpretation and identification of unforeseen presence

or consequences of assumptions. In addition, transporting the reader into the narrative was addressed by providing a narrative rich with my reflections and direct quotes from participant stories.

Discussion

I engaged in this inquiry to understand the characteristics and dimensions of participants' reality of "knowing the right action to take" in situations of moral distress. In addition to exploring "knowing the right action to take," I examined the contextual background of both participants and the clinical environment, in which the participants described knowing the right action to take within the context of moral distress.

An aspect of "knowing the right action to take" has been explored in nurses in the literature and was referred to by Lichtenburg (1994) as moral certainty. Nurses "knew" and then acted on the "right action" based on the nurses' not wanting to have regrets over inaction, in other words, a strong tendency for action rather than inaction. In discussing the study's results, which did not incorporate moral distress, Lichtenburg cautioned that acting from a position of moral certainty, omitted the step of reflection prior to taking the action. Within the moral distress literature, Repenshek (2009) termed this "knowing" as moral subjectivity, with actions reflective of one's individual moral integrity. Vaiani (2009) pushed the concept further to include moral certitude, in which the individual believed so strongly about "being right" that there is only one "right" course of action that is based on the individual's perspective.

An important point of discussion for this study involves the overriding presence of assumptions participants made in "knowing the right action to take." These assumptions seemed to play a significant role in participants' certainty about being right, as a potential precursor to moral distress. Reflecting on my own experience as a public health nurse when I visited some of

the graduates of the neonatal intensive care unit where I had practiced as a new graduate, I realized that I cannot and should not assume that what I want is what my patients would want.

The context of morally distressing situations described by participants in this study were in keeping with the consistent findings of other studies and included: participant perceptions of futile care and care not in the best interest of patients, care at the insistence of families to extend life, incompetence for the level of care needed, giving false hope to patients and families, and poor communication between members of the health care team (Caitlin et al., 2008; Corley, 1995; Corley, Minick, Elswick, & Jacobs, 2005; Hamric & Blackwell, Pauly, Varcoe, Storch, & Newton, 2009; 2007; Zuelo, 2007). These findings were reported as underlying causes of moral distress. From the results of the current study, I suggest instead, that participants' underlying assumptions of "knowing the right action," acted as a precursor to moral distress, rather than the situation that participants expressed as morally distressing.

Several sources in the literature instruct nurses to stand up and speak out for what they believe is right, or conscientiously object to what they believe is not right, to reduce the potential for moral distress, without first exploring the initial process of determining the "right action to take" (American Association of Critical Care Nurses, 2004; Caitlin et al., 2008). A negative relationship between ineffective communication and moral distress had been previously noted (Gordon & Hamric, 2006), although not with an exploration of "being certain of the right action" as it related to moral distress. The findings of this study highlight underlying participant assumptions in deciding communication strategies, which led to unsatisfactory outcomes for the participant.

The Joint Commission (2012) incorporates expectations that health care organizations must have a mechanism for resolving ethical dilemmas. Similar to other published findings

(Gordon & Hamric, 2006), participants in this study did not request assistance from their facility's ethics resources, raising a concern that ethics resources are potentially unknown to, not understood by, or not available to participants. Peter and Liaschenko (2004) discussed an inevitable ambiguity of nurses' moral duties, due to the close sustained proximity of nurses to patients. Ambiguity, it was suggested, can help individuals raise questions about the right action to take. Without resources to increase collaboration within and between disciplines and facilitate an understanding of multiple views of "the right thing," the nurse is left with his/her individual perspective.

A sense of isolation characterized participants' experiences of "knowing the right action to take." Within their isolation, participants held fast to their own beliefs of what was right for themselves and society as a self preserving mechanism. Available literature has addressed the benefits of an interdisciplinary team (IDT) approach in reducing the development and relief of moral distress (Deady, 2012; Deady & McCarthy, 2010; De Veer, Francke, Struijs, & Willems, 2012). A hallmark of hospice and palliative care, long term care, and physical rehabilitation, IDT's are commonly considered a strategy for approaching difficult situations and generally include the following disciplines: nurses, physicians, chaplains, therapists, social workers, and dieticians (DeLoach, 2003; Fulmer, et al., 2005; Strasser, Falconer, & Martino-Saltzman, 1994; Wittenberg-Lyles, Oliver, Demiris, & Courtney, 2007). Patients and families are considered a crucial part of the team and their input is paramount to developing a plan of care. While widely advocated in the literature, evidence of an IDT was generally absent in the experiences shared by participants. Also absent in most participant narratives was reflection on their own personal views. Engagement with members of an IDT could have created opportunities for reflection and evaluation of individual personal perspectives and conclusions.

Limitations

This was a qualitative study and as such the findings were not intended to be generalizable. While the sample size was small, participants had a range of demographic characteristics (age, gender, ethnicity, years of practice, education). All participants were practicing in adult critical care units in one geographic location in the mid-Atlantic region of the United States. The understandings derived from the study are necessarily historically and temporally situated and based on the experiences of the study participants who were employed in adult critical care settings and who had experienced moral distress within the context of their professional experience.

Finally, the questions I posed to participants (see Table 3) framed the problem in those terms and may have had an unintended consequence of leading the participants in a predetermined direction. Question 2, “Where and when in your career did this occur?” An alternative would have been to explore the aspects of the situation that were particularly problematic. Question 4, asked “Tell me about the barriers or obstacles to carrying out the right action.” Instead of soliciting what got in the way, an alternative would have been to explore what was absent that might have helped resolve the scenario.

Recommendations for Practice

Qualitative studies provide data and insights that can sensitize readers to possible problems and solutions in their own settings. For those who work in critical care units, the findings of this study suggest making visible the processes associated with individuals “knowing the right thing to do.” The isolation experienced by participants in this study may be a common phenomenon that could be addressed if recognized. Clinicians in the unique settings could then develop appropriate enhancements to reduce isolation. While not the focus of this study,

strategies for addressing isolation could include modifications to unit orientation to systematically create effective communication systems as well as establishing opportunities for reflection with an experienced mentor. The development of effective interdisciplinary teams in the critical care unit could also reduce isolation and systematically provide a range of perspectives for consideration in determining “the right thing to do.” Implementing strategies whereby ethics consultations are reconceptualized as routine clinical “ethics rounds” could possibly address the isolation experienced by participants in this study.

Recommendations for Future Research

A follow-up study with these participants could help explore if there are times while working in critical care when they had a sense of “knowing the right thing to do” but did not experience moral distress. Future research is also needed in nurses whose first nursing employment was in critical care, with the focus on how their nursing education programs prepared them to recognize and address their own assumptions about what is “right” as well as situations of isolation. Additional research is needed to understand why some nurses experience moral distress and others do not, possibly incorporating Corley’s (2000) theory of moral distress. Also missing in the literature are interventions to prevent and or decrease the experience of moral distress. Anecdotal interventions for moral distress through ethics facilitated discussions can be found in the literature that to date have not been studied (Babgi, Rogers, Gomez & McMahon, 2008; Heft, Bledsoe, & Hancock, 2009; Rogers, Babgi, & Gomez, 2008). Finally, because moral distress is not limited to nurses, research that explores more appropriate and beneficial ways to help relieve stress in all healthcare disciplines is important in supporting this work. An example of such research would be to focus on building interdisciplinary teams in critical care.

Conclusion

The significance of this study highlights an exploration of “knowing the right thing to do”, in the absence of resources, leading the nurse to fall back on what she/he believes is right for themselves, under circumstances similar to those of the patient. Published research addressing nurse moral distress has focused on describing moral distress without exploring the possibility that the RN may play a role in the development of his/her own moral distress. In this interpretive study, using narrative inquiry, a shared narrative was constructed and reconstructed, in which participants “recognized” or “knew” the right action as they considered the situation within its context and their own personal context. Participants determined what was right, from their own perspective, based on “doing good” and avoiding a sense of failure that would come from “not doing good.” Situations of isolation and an absence of resources to provide alternate “knowing” were highlighted. Assumptions that participants made about being certain of the right action to take were identified. Recommendations were provided for future research to better understand how to recognize and address the challenges associated with acting on an unexamined and personally-mediated view of “the right thing to do.”

**Table 1.0 Demographic Characteristics of
Study Sample (n = 10)**

Age Range (m=42):	
25-34	4
35-44	1
45-54	2
≥55	3
Gender:	
Male	3
Female	7
Ethnicity:	
African-American	2
Caucasian	6
Hispanic	1
Pacific Island-Asian	1
Employment Setting:	
Academic Medical Center	9
Community Hospital	1
Clinical Work Setting:	
Medical ICU	4
Surgical ICU	6
Nursing Education Level:	
Alternate degree to AD	1
Diploma	1
Bachelor's Degree	3
Alternate degree to BSN	3
Master's Degree	2
Years of Experience (m=14):	
<5	3
5-9	2
10-14	1
15-24	2
≥25	2

Table 2.0 Assumptions Identified from Participant Narratives

<p>Social construction of “knowing the right action to take” in Morally distressing situations.</p>	<p>Nurses do good suggesting that others therefore did not or were potentially not as good.</p> <p>Nurses are patient advocates, nurses care, and nurses know the patient implying that others in health care were not patient advocates, did not care to the degree that participants did, did not know the patient as well as participants did, and therefore did not know what was the “right action”.</p> <p>Doing good was exemplified by patients leaving critical care functionally and cognitively intact and anything less, especially death, meant failure.</p>
<p>Contextual background for participant experiences of moral distress.</p>	<p>Nurses are powerless and therefore cannot impact change.</p> <p>If the nurse did not see change, change either did not or would not occur.</p> <p>Resources for managing morally distressing situations were unavailable, did not exist, or were too much trouble to access.</p>
<p>Contextual perspectives for participant experiences of “knowing the right action to take” as it related to moral distress.</p>	<p>Decisions were made based on what the participant viewed as quality of life. If the participant did not want “it”, others would not want it either.</p> <p>Resources should not be allocated to those who are “undeserving”, patients who “have let themselves go”, are prisoners, or are non-compliant with their health care regimen.</p> <p>Patients who are intubated lack decision-making capacity, automatically shifting medical power to surrogates.</p> <p>When the perceived actions of others differed from what participants believed were or should be occurring, ulterior motivations were assumed.</p> <p>Family members shared the same beliefs and values as participants, and therefore families made “wrong” decisions because they did not have the enough information or the correct information.</p>

Table 3.0 Interview Questions

1. Tell me about a situation, in which you experienced moral distress.
2. Where and when in your career did this occur?
3. Tell me more about being certain you knew “the right thing” to do in this situation.
4. Tell me about the barriers or obstacles to carrying out the “right action” in this situation.
5. Is there anything else you’d like to tell me?

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“BEING CERTAIN”: MORAL DISTRESS IN CRITICAL CARE NURSES

Appendices: Institutional Review Board Submission and Approval

Appendix A – VCU Research Plan

Appendix B – Recruitment Narrative

Appendix C – Interview Questions

Appendix D – Demographic Form

Appendix E – IRB Approval of Research Study

Appendix A

Rev. Date: 6-1-11

VCU RESEARCH PLAN TEMPLATE

Use of this template is required to provide your VCU Research Plan to the IRB. Your responses should be written in terms for the non-scientist to understand. If a detailed research protocol (e.g., sponsor's protocol) exists, you may reference specific sections of that protocol. **NOTE: If that protocol does not address all of the issues outlined in each Section Heading, you must address the remaining issues in this Plan. It is NOT acceptable to reference a research funding proposal.**

ALL Sections of the Human Subjects Instructions must be completed with the exception of the Section entitled "Special Consent Provisions." Complete that Section if applicable. When other Sections are not applicable, list the Section Heading and indicate "N/A."

NOTE: The Research Plan is required with ALL Expedited and Full review submissions and MUST follow the template, and include version number or date, and page numbers.

DO NOT DELETE SECTION HEADINGS OR THE INSTRUCTIONS.

I. TITLE

II. RESEARCH PERSONNEL

A. PRINCIPAL INVESTIGATOR

List the name of the VCU Principal Investigator

D. Patricia Gray, PhD

C. Describe the process that you will use to ensure that all persons assisting with the research are adequately informed about the protocol and their research-related duties and functions.

The Student Researcher, Marian Baxter, has completed all requisite course work including research course received individual mentoring in the conduct of qualitative inquiry. She was involved in all aspects of developing research protocol. She will coordinate participant recruitment and conduct all research interviews. The student for on-going and regular oversight of the student researcher's work are described in the section on rigor (st interviews are professionally transcribed, the transcriptionist will have completed human subjects training required to sign a confidentiality statement.

III. CONFLICT OF INTEREST

Describe how the principal investigator and sub/co-investigators might benefit from the subject's participation in this project or completion of the project in general. Do not describe (1) academic recognition such as publications or (2) grant or contract based support of VCU salary commensurate with the professional effort required for the conduct of the project

The investigators will not benefit from the research participants participation or completion of this research project.

IV. RESOURCES

Briefly describe the resources committed to this project including: (1) time available to conduct and complete the research, (2) facilities where you will conduct the research, (3) availability of medical or psychological resources that participants might require as a consequence of the research (if applicable), and (4) financial support.

1. 100% of the student researcher's time will be available at no cost to conduct and complete the research.
2. Participant interviews will be conducted at an accessible location selected by the participant. Data will be analyzed at the School of Nursing and the student researcher's home.
3. This research study presents no more than minimal risk to participants. In the unlikely event that participants become emotionally upset during the interview, they will have the choice to end the interview and they will be encouraged to seek support from a counselor or other appropriate person and the participant will be informed that this support will not be at a cost to the project.
4. No financial support is available.

V. HYPOTHESIS

Briefly state the problem, background, importance of the research, and goals of the proposed project.

Moral distress has been identified by Jameton (1984, 1993) as a negative experience, in which a nurse finds the right action to take, but is unable to carry out that right action due to institutional barriers. There has been exploration of the moral certitude that leads to "knowing the right action to take," a precursor to moral distress. An interpretive study design will be used to develop an understanding of the experience of being certain of "the right action to take" as it relates to nurses' professional experiences of moral distress. The research question to be addressed is: "For critical care nurses who have experienced moral distress in the clinical practice setting, how is being certain of the right action(s) to take" recognized and understood?"

VI. SPECIFIC AIMS

The proposed study will address the following specific aims:

1. Develop an understanding of the contextual background for each participant's experiences of moral distress.
2. Develop an understanding of the contextual perspectives for each participant's experiences of "being certain of the right action to take" as it relates to moral distress.
3. Examine the social construction of "being certain of the right action to take" in morally distressing situations.

VII. BACKGROUND AND SIGNIFICANCE

Include information regarding pre-clinical and early human studies. Attach appropriate citations.

The term "moral distress" was coined in 1984 and defined as a negative experience, in which a nurse knows the right action to take, but is unable to carry out that right action due to institutional barriers (Jameton, 1993). Failure to alleviate moral distress can impact patient care, lead to job stress and staff turnover, and cause nurses to leave the profession (Caitlin et al., 2008; Corley, 1995; Fry, Harvey, Hurley, & Foley, 2002; Gur Thomas, 2006; Gutierrez, 2005; Hamric & Blackhall, 2007; Millette, 1994; Pendry, 2007).

Moral distress was proposed as a nursing diagnosis in 2005 and accepted at the North American Nursing Association, Nursing Interventions Classification, and Nursing Outcomes Classification Conference (NNN) in Philadelphia in March, 2006 (Scroggins, 2006). Although moral distress is not limited to nurses, it is thought to be especially prevalent in nurses because of the practice hierarchy that positions nurses in the middle, between patients and families, and physicians, creating the opportunity for moral tension (Engelhardt, 2001). Others have offered that because of the close proximity of nurses to patients, nurses are more likely to experience moral distress than are members of other health professions (Peter & Liaschenko, 2004). Another interpretation

distress moved it beyond an experience to "...a negative state of psychological disequilibrium" (Wilkinson, 1987, p.16). Two forms of moral distress have been distinguished: initial and reactive (Jameton, 1993). In addition, long after the morally distressing situation has ended, negative effects of moral distress can linger in what Webster and Baylis termed moral residue (2000). The American Association of Critical Care Nurses (AACN) Public Policy Position Statement: Moral Distress, defined moral distress as occurring when "you know the ethically appropriate action to take, but are unable to act upon it and you act in a manner contrary to your personal and professional values, which undermines your integrity and authenticity" (2008, p.1). Equally present in the literature, were citations of Corley's work in identifying situations that can lead to moral distress, potential consequences for the individual nurse, and the negative impact on the profession as a whole (Corley, 1995; Corley, 2002; Corley, Elswick, Gorman, & Clor, 2001; Corley, Minick, Elswick, & Jacobs, 2005). The exceptions to the above were six articles that preceded Corley's work (Fenton, 1988; Jameton, 1984; Jameton, 1993; Millette, 1994; Wilkinson, 1987; and Wilkinson, 1989). One cause of moral distress evident throughout the literature involved situations in which a nurse was delivering care that the nurse identified as not in the patient's best interest. This one possible avenue for the nurse to conclude that he or she knows "the right action to take," however how nurses reach this conclusion has not been systemically examined. Since "knowing the right action to take" is a precursor to the experience of moral distress, a better understanding of its construction is needed.

VIII. PRELIMINARY PROGRESS/DATA REPORT

If available.

NA

X. PLAN FOR CONTROL OF INVESTIGATIONAL DRUGS, BIOLOGICS, AND DEVICES.

Investigational drugs and biologics: IF Investigational Drug Pharmacy Service (IDS) is not being used, attach the IDS confirmation of receipt of the management plan.

Investigational and humanitarian use devices (HUDs): Describe your plans for the control of investigational devices and HUDs including:

- (1) how you will maintain records of the product's delivery to the trial site, the inventory at the site, the use by each subject, and the return to the sponsor or alternative disposition of unused product(s);
- (2) plan for storing the investigational product(s)/ HUD as specified by the sponsor (if any) and in accordance with applicable regulatory requirements;
- (3) plan for ensuring that the investigational product(s)/HUDs are used only in accordance with the approved protocol; and
- (4) how you will ensure that each subject understands the correct use of the investigational product(s)/HUDs (if applicable) and check that each subject is following the instructions properly (on an ongoing basis).

NA

XI. DATA ANALYSIS PLAN

For investigator-initiated studies.

Quantitative demographic data will be summarized and used to describe characteristics of the study in research reports. An iterative approach to qualitative data generation and analysis will be used to allow on-site selection, interview, and analysis of data and to facilitate maximum variation sampling. Shortly after each recording will be transcribed into text format by the researcher or a transcriptionist who has completed human transcription training. Transcribed text will serve as the data for analysis, along with field notes and the personal journal. Data will be analyzed according to the methods and procedures outlined by Clandinin and Connelly. The approach to interpretive narrative analysis does not consist of a series of steps, but rather considers the following:

- Make field notes while listening and re-listening to the recordings.
- Read and re-read the transcripts.

- Read and re-read the field notes and reflective journal.
- Initial analysis captures character, place, scene, plot, tension, end point, narrator, context, and tone. These initial analyses are not constructed with reflective intent.
- Compose field texts (interpretive process, expresses the relationship of researcher to participant, note researcher selectivity: what is unsaid as much as what is said).
- Ask questions of meaning and social significance of transcriptions.
- Transition from above composed field texts to what Clandinin and Connelly (2000) refer to as research texts to include patterns, narrative threads, tensions, and themes within and across the participants' experiences.

Methodological Rigor: steps will be taken to ensure rigor of both study processes and study outcomes, based on Lincoln and Guba's criteria for trustworthiness (1985). The four elements of trustworthiness include credibility, transferability, dependability, and confirmability. Operational techniques of each element are described as follows:

- Credibility – activities that increase the likelihood that the findings and outcomes are credible and that provide an external check on study processes: purposeful sampling (iterative), audio-taped interviews, verbatim transcription, reflective journal, and an audit trail
- Transferability – purposeful sampling (iterative), 'thick' description and reflective journal that allow readers to reach conclusions about the possibility of transferring the results and conclusions.
- Dependability – techniques that strengthen the study claims: reflective journal, peer debriefing and peer review using de-identified data, reflective journal
- Confirmability – reflective journal and audit trail to substantiate that the findings are grounded in the data.

The researcher's steps and decision-making will be documented in the reflective journal. An audit process will be implemented throughout the study to ensure adherence to the methods of Clandinin and Connelly (2000). Ongoing meetings with dissertation advisor and committee members will be conducted to assess study progress and review interpretations of interview data. Using de-identified data, peer debriefing will be conducted during data analysis and interpretation phases with a minimum of two to three selected professional nursing colleagues who have extensive expertise in nursing and/or critical care. Peer de-briefing will provide the opportunity for on-going response and feedback of data interpretation and unforeseen presence or consequences of assumptions.

Study Limitations: This is a qualitative study and as such the findings are not intended to be generalizable. The understandings derived from the study will be historically and temporally situated and based on the experiences of the study participants who are employed in critical care settings and who have experienced moral distress in the context of their professional experience.

XII. DATA AND SAFETY MONITORING

- **If the research involves greater than minimal risk and there is no provision made for data and safety monitoring by any sponsor, include a data and safety-monitoring plan that is suitable for the level of risk to be faced by subjects and the nature of the research involved.**
- **If the research involves greater than minimal risk, and there is a provision made for data and safety monitoring by any sponsor, describe the sponsor's plan.**
- **If you are serving as a Sponsor-Investigator, identify the Contract Research Organization (CRO) that you will be using and describe the provisions made for data and safety monitoring by the CRO. Guidance on additional requirements for Sponsor-Investigators is available at <http://www.research.vcu.edu/irb/wpp/flash/X-2.htm>**

This research involves no more than minimal risk to participants. It is possible that some nurses may experience emotional distress during the interview as they discuss their experience with moral distress. The use of nursing and pseudonyms in reports of the study will ensure confidentiality. All material associated with the study is stored in a fire-proof locked file cabinet in the VCU School of Nursing.

XIII. MULTI-CENTER STUDIES

If VCU is the lead site in a multi-center project or the VCU PI is the lead investigator in a multi-center project, describe the plan for management of information that may be relevant to the protection of subjects, such as reporting of unexpected problems, project modifications, and interim results.

NA

XIV. INVOLVEMENT OF NON-VCU INSTITUTIONS/SITES (DOMESTIC AND FOREIGN)

1. Provide the following information for each non-VCU institution/site (domestic and foreign) that has agreed to participate:

- Name of institution/site
- Contact information for institution/site
- Engaged in Research or not (if YES AND the research involves a DIRECT FEDERAL AWARD made to VCU, include FWA #). See OHRP’s guidance on “Engagement of Institutions in Research” at <http://www.hhs.gov/ohrp/policy/engage08.html>.
- Request for the VCU IRB to review on behalf of the Non-VCU institution? See requirements found at <http://www.research.vcu.edu/irb/wpp/flash/XVII-6.htm>.
- See VCU WPPs:

<http://www.research.vcu.edu/irb/wpp/flash/XVII-6.htm> and
<http://www.research.vcu.edu/irb/wpp/flash/XVII-11.htm>.

Name of Institution	Contact Information for Site	Engaged (Y/N) and FWA # if applicable	Request for review or non-VCU
NA			

*NOTE: If a Non-VCU site is engaged in the research, the site is obligated to obtain IRB review or request that the VCU IRB review on its behalf.

2. Provide a description of each institution’s role (whether engaged or not) in the research, adequacy of the facility (in order to ensure participant safety in the case of an unanticipated emergency), responsibilities of its agents/employees, and oversight that you will be providing in order to ensure adequate and ongoing protection of the human subjects. You should only identify institutions that have agreed to participate. If additional institutions agree to participate at a later time, they must be added by amendment to the protocol.

NA

XV. HUMAN SUBJECTS INSTRUCTIONS

ALL sections of the Human Subjects Instructions must be completed with the exception of the section entitled “Special Consent Provisions.” Complete that section if applicable.

A. DESCRIPTION

Provide a detailed description of the proposed involvement of human subjects or their private identifiable data.

A maximum variation sample of an anticipated maximum of 15 registered nurses (RN) will participate. Inclusion criteria for the study will consist of the following: current employment as an RN in an inpatient c

either in an academic or community hospital setting, speak and understand English, and self identified as having experienced moral distress as a result of professional work experiences. Moral distress is defined as a negative experience in which a nurse is certain of the right action to take, but is unable to carry out that right action due to institutional barriers. **(A copy of the recruitment narrative is attached to this document.)**

After explaining the purpose of the study and answering initial questions, the researcher will assess whether the interested RN meets the inclusion criteria. As participants are enrolled in the study, demographic data will be obtained. Demographic data from all participants will be aggregated and summarized on an on-going basis. Individual and aggregated data will contribute to the description of the study sample in written research reports. **(A copy of the demographic data form is attached to this document.)**

Interviews will be conducted individually with each participant. Interviews are expected to last up to 60 minutes and will be audio-taped. All interviews will be conducted in a private, quiet area in a setting that is convenient to the participant. Permission will be obtained from each participant for future contact for clarification of information from the interview session, through a method selected by the participant (e-mail, phone, or mail). **(A copy of the interview questions is attached to this document.)**

B. SUBJECT POPULATION

Describe the subject population in terms of sex, race, ethnicity, age, etc., and your access to the population that will allow recruitment of the necessary number of participants. Identify the criteria for inclusion or exclusion of all targeted populations and include a justification for any exclusions. Explain the rationale for the involvement of special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable. If you plan to allow for the enrollment of Wards of the State (or any other agency, institution, or entity), you must specifically request their inclusion and follow guidance in VCU IRB WPP XV-3: Wards and Emancipated Minors available at <http://www.research.vcu.edu/irb/wpp/flash/XV-3.htm>.

The study population is employed nurses who work in critical care units that speak and understand English and have had experiences of moral distress in the practice setting. As a result, study participants will be mental non-incarcerated adults. There are no restrictions on the race, ethnicity, or gender of participants, although the population of registered nurses tends to be predominantly female and Caucasian.

C. RESEARCH MATERIAL

Identify the sources of research material obtained from individually identifiable living human subjects in the form of specimens, records, or data. Indicate whether the material or data will be obtained specifically for research purposes or whether use will be made of existing specimens, records, or data.

Research material will consist of participant demographic data, audio-recorded interviews, electronic and interview transcripts, researcher field notes, and researcher reflection journal. All material from this study is for the sole purpose of research. All data will be de-identified. No data will be stored directly on the computer. A thumb drive will be used for maintaining electronic data. A back-up disk will also be used to facilitate protection of data. The audio-recorder and disks containing electronic transcribed interview text, as well as all other research materials, will be safeguarded in a locked fire-proof container that is stored in the VCU School of Nursing. All data from this study will be destroyed according to the policies and guidelines of Virginia Commonwealth University Office of Research.

D. RECRUITMENT PLAN

Describe in detail your plans for the recruitment of subjects including:

- (1) how potential subjects will be identified (e.g., school personnel, health care professionals, etc),**
 - (2) how you will get the names and contact information for potential subjects, and**
 - (3) who will make initial contact with these individuals (if relevant) and how that contact will be done.**
- If you plan to involve special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable, describe any special recruitment**

procedures for these populations.

Recruitment of potential participants will be accomplished through posting of the information flyer at nurse-accessible locations within Virginia Commonwealth University Health System's critical care areas, distribution of information about the study to personal professional contacts. In addition, the researcher will provide information about the study to members of the Richmond area chapter of American Association of Critical Care Nurses (AACN), via its list-serve. Following IRB approval, formal permission will be obtained from AACN to disseminate information about the study.

The information flyer will include instructions for those RNs who are interested to contact the researcher by phone, e-mail, or in person. Once a nurse interested in participating in the study contacts the researcher, they will explain the purpose of the study, answer any questions, and assess whether the interested nurse meets the inclusion criteria for the study are as follows: current employment as RN in a critical care setting, ability to understand English, and self-identification as having experienced moral distress within the context of professional experience.

If the interested RN does not meet the inclusion criteria, the researcher will inform the RN and thank them for their interest in the study. If inclusion criteria are met, the RN will be informed that the study includes a face-to-face, audio-recorded 60 minute interview to explore the nurse's experience of moral distress. The RN will also be informed that the responses will not be personally identified with him/her. If the potential participant expresses interest in participating, the RN will be asked to meet the researcher at a private and quiet location convenient to the participant, to receive an information packet that includes details about the study and the informed consent form. The participant will be given time to read the document, have any questions answered, and if appropriate, to complete the informed consent form. Once the informed consent form is completed, the interview will be conducted. **(A copy of the recruitment information flyer is attached to this document.)**

E. PRIVACY OF PARTICIPANTS

NOTE: Privacy refers to individuals and their interests in controlling access to their identities, their physical person, and how and what kind of information is obtained about them. Privacy also encompasses the interests of defined communities (e.g. those with a certain diagnosis or social circumstance) in controlling access to the group identity and information about the group or individuals as part of the group.

Describe how the privacy interests of subjects (and communities, if appropriate) will be protected including:

- (1) in the research setting (e.g., in the identification, recruitment, and intervention settings) and**
- (2) with the information being sought and the way it is sought. For example, providing drapes or barriers, interviewing in a private room, and collecting only the amount of sensitive information needed for identification, recruitment, or the conduct of the study.**

To facilitate participant privacy and comfort with the process, the following steps will be taken: each participant will be given the opportunity to select a private location for the interview; informed consent and permission to audio-record the interview will be obtained; all data will be de-identified; participants will be informed and reminded that they may stop the interview and/or withdraw from the study at any time, without consequences.

F. CONFIDENTIALITY OF DATA

NOTE: Confidentiality refers to the way private, identifiable information about a subject or defined community is maintained and shared.

Check all of the following precautions that will be used to maintain the confidentiality of identifiable information:

- Paper-based records will be kept in secure location and only accessed by authorized study personnel
- Electronic records will be made available only to those personnel in the study through the use of

access controls and encryption

Identifiers will be removed from study-related data (data is coded with a key stored in a separate secure location)

For research involving web-based surveys, data is secured via passwords and encryption

Audio or video recordings of subjects will be transcribed and then destroyed to prevent audio or visual identification. Note the date of destruction (e.g., 3 months from close of study; after transcription is determined to be error free).

Obtaining a Certificate of Confidentiality

Other precautions: **NA**

G. POTENTIAL RISKS

Describe potential risks (physical, psychological, social, legal, or other) and assess their likelihood and seriousness. Where appropriate, describe alternative treatments and procedures that might be advantageous to the subjects.

This research presents no more than minimal risk to the participants. It is possible that some nurses may experience temporary emotional distress during the interview as they describe their experience with moral distress. There are no alternative treatments.

H. RISK REDUCTION

Describe procedures for protecting against or minimizing potential risk. Where appropriate, discuss provisions for ensuring necessary medical or professional intervention in the event of adverse events to the subjects. Describe the provisions for monitoring the data collected to ensure the safety of subjects, if any.

The risks associated with this study are minimal. In order to facilitate participant comfort with the interview, the following steps will be implemented: participants will be given the opportunity to select the interview location; consent will be obtained and permission sought for use of audio recording of the interview; all data will be stored securely; participants will be reminded that they can stop the interview and/or withdraw from the study at any time. The researcher will be observant of any personal discomfort and negative emotions of participants. If the participant demonstrates personal or emotional distress or discomfort, the interview will be temporarily stopped and the participant will be given the option to continue the interview, reschedule the interview, or withdraw from the study. The participant will be informed that they can seek support from a counselor or other appropriate person and the participant will be informed that this will not result in cost to the project.

I. ADDITIONAL SAFEGUARDS FOR VULNERABLE PARTICIPANTS

Describe any additional safeguards to protect the rights and welfare of participants if you plan to involve special cases of subjects such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable.

Safeguards to protect the rights and welfare of participants might relate to Inclusion/Exclusion Criteria: (“Adults with moderate to severe cognitive impairment will be excluded.” “Children must have diabetes. No normal controls who are children will be used.”) Consent: (“Participants must have an adult care giver who agrees to the participant taking part in the research and will make sure the participant complies with research procedures.” “Adults must be able to assent. Any dissent by the participant will end the research procedures.”) Benefit: (“Individuals who have not shown benefit to this type of drug in the past will be excluded.”).

NA

J. RISK/BENEFIT

Discuss why the risks to participants are reasonable in relation to the anticipated benefits to subjects and in relation to the importance of the knowledge that may reasonably be expected to result. If a test article (investigational new drug, device, or biologic) is involved, name the test article and supply the FDA approval letter.

There are no direct benefits to participants, except to the extent that reviewing past experiences may be helpful in generating new personal insights into one's thinking or behaving. The knowledge gained from this study has the potential to make significant contributions to the understanding of moral distress. Thus the minimal risk to participants is in relation to the benefit of increased knowledge.

K. COMPENSATION PLAN

Compensation for participants (if applicable) should be described, including possible total compensation, pro-rating, any proposed bonus, and any proposed reductions or penalties for not completing the project.

Participants will not be compensated for participating in the study and there will be no penalties for not completing the project.

L. CONSENT ISSUES

1. CONSENT PROCESS

Indicate who will be asked to provide consent/assent, who will obtain consent/assent, what language (e.g., English, Spanish) will be used by those obtaining consent/assent, where and when will consent/assent be obtained, what steps will be taken to minimize the possibility of coercion or undue influence, and how much time will subjects be afforded to make a decision to participate.

1. Consent process – the following considerations will be included:
 - Who will be asked to provide consent/assent? **Potential participants (adult employed RNs working in a critical care that speak and understand English and that have experienced moral distress in a hospital setting)**
 - Who will obtain consent/assent? **The student researcher will obtain consent.**
 - What language will be used by those obtaining consent/assent? **English language will be used.**
 - Where and when will consent/assent be obtained? **After providing the description of the study, consent will be obtained prior to beginning the interview.**
 - What steps will be taken to minimize the possibility of coercion or undue influence? **Enrollment requires participants to contact the researcher to express interest in participation (A copy of the Recruitment Flyer is attached.)**
 - How much time will subjects be afforded to make a decision to participate? **Potential participants will be asked if they would like to make a decision to participate after talking with the student researcher. The potential participants will be asked to call the student researcher to schedule an appointment once they decide they would like to participate.**
2. Consent setting – The student researcher will explain the study prior to distributing the informed consent form which outlines the purpose of the study, risks and benefits of the study, and assuring that confidentiality will be maintained. Participants will be informed about the investigator's availability to answer any questions that may arise during the review of distributed materials. The informed consent process will be completed by the student researcher. Contact information for the student researcher, Principal Investigator (PI), and the Office of Human Subjects Protection is provided to participants so that any questions may be answered. The Research Information and Consent form is attached to the document.
3. Comprehension – Participants will be registered nurses and thus should be able to understand the nature of the study as their involvement and rights concerning the study. The investigators will be available to answer any questions related to the study. English language will be used.

2. SPECIAL CONSENT PROVISIONS

If some or all subjects will be cognitively impaired, or have language/hearing difficulties, describe how capacity for consent will be determined. Consider using the VCU Informed Consent Evaluation Instrument available at <http://www.research.vcu.edu/irb/guidance.htm>. If you anticipate the need to obtain informed consent from legally authorized representatives (LARs), please describe how you will identify an appropriate representative and ensure that their consent is obtained. Guidance on LAR is available at <http://www.research.vcu.edu/irb/wpp/flash/XI-3.htm>.

NA

3. ASSENT PROCESS

If applicable, explain the Assent Process for children or decisionally impaired subjects. Describe the procedures, if any, for re-consenting children upon attainment of adulthood. Describe procedures, if any, for consenting subjects who are no longer decisionally impaired. Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XV-2.htm> and <http://www.research.vcu.edu/irb/wpp/flash/XVII-7.htm>.

NA

4-A. REQUEST TO WAIVE SOME OR ALL ELEMENTS OF INFORMED CONSENT FROM SUBJECTS OR PERMISSION FROM PARENTS: A waiver of informed consent means that the IRB is not requiring the investigator to obtain informed consent OR the IRB approves a consent form that does not include or alters some/all of the required elements of consent. Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XI-1.htm>. **NOTE:** Waiver is not allowed for FDA-regulated research unless it meets FDA requirements for Waiver of Consent for Emergency Research (see below).

4-A.1. Explain why a waiver or alteration of informed consent is being requested.

NA

4-A.2. Describe how this study meets **ALL FOUR** of the following conditions for a waiver or alteration:

- The research involves no more than minimal risk to the participants. → Explain how your study meets this criteria:
- The waiver or alteration will not adversely affect the rights and welfare of participants. → Explain how your study meets this criteria:
- The research could not practicably be carried out without the waiver or alteration. → Explain how your study meets this criteria:
- Will participants be provided with additional pertinent information after participation?
 Yes
 No → Explain why not:

4-B. REQUEST TO WAIVE DOCUMENTATION OF CONSENT: A waiver of documentation occurs when the consent process occurs but participants are not required to sign the consent form. Guidance is available at http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XI-2.htm. One of the following two conditions must be met to allow for consenting without signed documentation. Choose which condition is applicable and explain why (explanation required):

The only record linking the participant and the research would be the informed consent form. The principal risk to the participant is the potential harm resulting from a breach of confidentiality. Each participant will be asked whether he/she wants documentation linking the participant with the research and the participants wishes will govern. → Explain how your study fits into the category:

The research presents no more than minimal risk of harm to participants & involves no procedures for which signed consent is normally required outside of the research context. → Explain how your study fits into the category:

4-C. REQUEST TO WAIVE SOME OR ALL ELEMENTS OF ASSENT FROM CHILDREN ≥ AGE 7 OR FROM DECISIONALLY IMPAIRED INDIVIDUALS: A waiver of assent means that the IRB is not requiring the investigator to obtain assent OR the IRB approves an assent form that does not include some/all of the required elements. Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XV-2.htm>.

4-C.1. Explain why a waiver or alteration of informed consent is being requested.

In order for the IRB to approve a request for waiver of assent, the conditions for 4-C.2, 4-C.3, OR 4-C.4 must be met. Check which ONE applies and explain all required justifications.

4-C.2. Some or all of the individuals age 7 or higher will not be capable of providing assent based on their developmental status or impact of illness. → Explain how your study meets this criteria:

4-C.3. The research holds out a prospect of direct benefit not available outside of the research. → Explain how your study meets this criteria:

4-C.4. Describe how this study meets **ALL FOUR** of the following conditions:

- The research involves no more than minimal risk to the participants. → Explain how your study meets this criteria:
- The waiver or alteration will not adversely affect the rights and welfare of participants. → Explain how your study meets this criteria:
- The research could not practicably be carried out without the waiver or alteration. → Explain how your study meets this criteria:
- Will participants be provided with additional pertinent information after participation?
 Yes
 No → Explain why not:

4-D. REQUEST TO WAIVE CONSENT FOR EMERGENCY RESEARCH: Describe how the study meets the criteria for emergency research and the process for obtaining LAR consent is appropriate. See guidance at <http://www.research.vcu.edu/irb/wpp/flash/XVII-16.htm>.

NA

5. GENETIC TESTING

If applicable, address the following issues related to Genetic Testing.

5-A. FUTURE CONTACT CONCERNING FURTHER GENETIC TESTING RESEARCH

Describe the circumstances under which the subject might be contacted in the future concerning further participation in this or related genetic testing research.

NA

5-B. FUTURE CONTACT CONCERNING GENETIC TESTING RESULTS

If planned or possible future genetic testing results are unlikely to have clinical implications, then a

statement that the results will not be made available to subjects may be appropriate. If results might be of clinical significance, then describe the circumstances and procedures by which subjects would receive results. Describe how subjects might access genetic counseling for assistance in understanding the implications of genetic testing results, and whether this might involve costs to subjects. Investigators should be aware that federal regulations, in general, require that testing results used in clinical management must have been obtained in a CLIA-certified laboratory.

NA

5-C. WITHDRAWAL OF GENETIC TESTING CONSENT

Describe whether and how subjects might, in the future, request to have test results and/or samples withdrawn in order to prevent further analysis, reporting, and/or testing.

NA

5-D. GENETIC TESTING INVOLVING CHILDREN OR DECISIONALLY IMPAIRED PARTICIPANTS

Describe procedures, if any, for consenting children upon the attainment of adulthood. Describe procedures, if any, for consenting participants who are no longer decisionally impaired.

NA

5-E. CONFIDENTIALITY OF GENETIC INFORMATION

Describe the extent to which genetic testing results will remain confidential and special precautions, if any, to protect confidentiality.

NA

Appendix B

Recruitment Narrative

Thank-you for contacting me about the research study, “Being certain”: Moral distress in critical care nurses, that is being conducted by researchers from Virginia Commonwealth University (VCU). The purpose of the study is to gain a better understanding of the experience of moral distress in critical care nurses. It will take about five minutes to hear more about this study. May I continue?

If you meet the criteria for the study, you will be invited to participate in a one-hour interview that focuses on your experience of moral distress, defined as the experience that occurs when a nurse is certain about the right action to take, but is unable to take the right action because of institutional barriers. The interviews will be audio-tape recorded. The information you share will not be identified with you. There will be no payment for your participation in the study. Your decision about whether to be in the study or not will not affect your current employment in any way. The criteria for inclusion in the study are:

- Current employment as a registered nurse in a critical care area,
- Having experienced moral distress in the practice setting,
- Ability to speak and understand English.

Do you meet these criteria?

If NO: Thank-you for your call. If you know others who may qualify and who may be interested, I would be grateful if you would tell them about this study and how to contact me.

If YES: Do you have any questions at this point?

If YES: Answer.

If NO questions: Would you be willing to meet at a location that is convenient to you to provide you with the informed consent document and answer any questions you have? At that time you can complete the informed consent document or take it with you and complete it later. I can also mail the informed consent document to an address of your choosing. Within a week of receiving the document, I will call you or ask you to contact me with any questions. Once you complete the document, please call me to schedule an appointment for the interview.

If Informed Consent to be mailed: To what address or email should I send the informed consent form?

Contact Information: Do you prefer to contact me or may I have your contact email address or phone number to answer any questions and schedule the interview if you decide to participate? Thank you for your time today. I look forward to speaking with you soon. Please let me know if you have any questions in the mean time. I can be reached at (804) 350-4347 or email mlbaxter@vcu.edu.

Appendix C

Interview Questions

1. Tell me about a situation in which you experienced moral distress.
2. Where and when in your career did this occur?
3. Tell me more about being certain you knew the right thing to do in this situation.
4. Tell me about the barriers or obstacles to carrying out the “right action” in this situation.
5. Is there anything else you’d like to tell me?

Appendix D

Demographic Information

Date _____

Age _____

Gender _____

ID# _____

Race _____

Entry Educational Preparation

___ Less than 1-year

___ 1-2 years

___ 3-5 years

___ 6-10 years

___ 11-15 years

___ Greater than 15

Years of Critical Care Nursing Practice

___ Diploma

___ Associate Degree in Nursing

___ Bachelor's Degree in Nursing

___ Alternate Degree to BSN

Highest Level of Education

___ Some College Coursework

___ Associate Degree in _____

___ College Degree in _____

___ Some Graduate School

___ Master's Degree in _____

___ Doctorate Degree in _____

Employment Setting

___ Academic Medical Center

___ Community Hospital

___ Federal Academic Facility

Current Practice Setting

___ Critical Care

___ Step-down Unit

___ Other (describe) _____

Years of Nursing Practice

___ Less than 1-year

___ 1-2 years

___ 3-5 years

___ 6-10 years

___ 11-15 years

___ Greater than 15

Appendix E

VCU Memo

V i r g i n i a C o m m o n w e a l t h U n i v e r s i t y

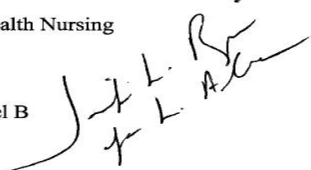
Office of Research Subjects Protection
BioTechnology Research Park
BioTech One, 800 E. Leigh Street, #114
P.O. Box 980568
Richmond, Virginia 23298-0568
(804) 828-3992
(804) 827-1448 (fax)

DATE: November 29, 2011

TO: D. Patricia Gray, PhD
School of Nursing, Adult Health Nursing
Box 980567

FROM: Lisa M. Abrams, PhD
Chairperson, VCU IRB Panel B
Box 980568

RE: **VCU IRB #: HM13981**
Title: "Being Certain": Moral Distress in Clinical Care Nurses



On November 28, 2011, the following research study was **approved** by expedited review according to 45 CFR 46.110 Category 6. This approval includes the following items reviewed by this Panel:

RESEARCH APPLICATION/PROPOSAL: None

PROTOCOL (Research Plan: "Being Certain": Moral Distress in Clinical Care Nurses, received 10/5/11, version 1, dated 9/25/11

- VCU IRB Study Personnel Roster, received 10/5/11, version 1, dated 9/25/11
- Demographic Information, received 10/5/11, version 1, dated 9/25/11
- Interview Questions, received 10/5/11, version 1, dated 9/25/11
- References, received 10/5/11

CONSENT/ASSENT (attached):

- Research Subject Information and Consent Form, received 10/5/11, version 1, dated 9/25/11, 3 pages

ADDITIONAL DOCUMENTS (attached):

- Flyer: Participants Needed for Research Study, received 10/5/11, version date 9/25/11
- Recruitment Narrative, received 10/5/11, version date 9/25/11

This approval expires on October 31, 2012. Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you prior to the scheduled review.

The Primary Reviewer assigned to your research study is Lou Usry, RN. If you have any questions, please contact Ms. Usry at lusry@mcvh-vcu.edu and 828-9229; or you may contact Jennifer Rice, IRB Coordinator, VCU Office of Research Subjects Protection, at irbpanelb@vcu.edu and 828-3992.

[Attachment – Conditions of Approval]

Conditions of Approval:

In order to comply with federal regulations, industry standards, and the terms of this approval, the investigator must *(as applicable)*:

1. Conduct the research as described in and required by the Protocol.
2. Obtain informed consent from all subjects without coercion or undue influence, and provide the potential subject sufficient opportunity to consider whether or not to participate (unless Waiver of Consent is specifically approved or research is exempt).
3. Document informed consent using only the most recently dated consent form bearing the VCU IRB "APPROVED" stamp (unless Waiver of Consent is specifically approved).
4. Provide non-English speaking patients with a translation of the approved Consent Form in the research participant's first language. The Panel must approve the translated version.
5. Obtain prior approval from VCU IRB before implementing any changes whatsoever in the approved protocol or consent form, unless such changes are necessary to protect the safety of human research participants (e.g., permanent/temporary change of PI, addition of performance/collaborative sites, request to include newly incarcerated participants or participants that are wards of the state, addition/deletion of participant groups, etc.). Any departure from these approved documents must be reported to the VCU IRB immediately as an Unanticipated Problem (see #7).
6. Monitor all problems (anticipated and unanticipated) associated with risk to research participants or others.
7. Report Unanticipated Problems (UPs), including protocol deviations, following the VCU IRB requirements and timelines detailed in VCU IRB WPP VIII-7:
8. Obtain prior approval from the VCU IRB before use of any advertisement or other material for recruitment of research participants.
9. Promptly report and/or respond to all inquiries by the VCU IRB concerning the conduct of the approved research when so requested.
10. All protocols that administer acute medical treatment to human research participants must have an emergency preparedness plan. Please refer to VCU guidance on <http://www.research.vcu.edu/irb/guidance.htm>.
11. The VCU IRBs operate under the regulatory authorities as described within:
 - a) U.S. Department of Health and Human Services Title 45 CFR 46, Subparts A, B, C, and D (for all research, regardless of source of funding) and related guidance documents.
 - b) U.S. Food and Drug Administration Chapter I of Title 21 CFR 50 and 56 (for FDA regulated research only) and related guidance documents.
 - c) Commonwealth of Virginia Code of Virginia 32.1 Chapter 5.1 Human Research (for all research).

010507

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: "Being Certain" – Moral distress in critical care nurses
VCU IRB NO.: H M 13981



This consent form may contain words that you do not understand. Please ask the study staff to explain any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY

The purpose of this research study is to find out about the experience of "being certain about the right thing to do" in a situation you found morally distressing while caring for a patient in critical care.

You are being asked to participate in this study because you have experienced a morally distressing situation while caring for a patient in a critical care unit.

DESCRIPTION OF THE STUDY

If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

In this study you will be asked to participate in an individual interview. The interview will last approximately one hour. You will be asked to talk about a situation in which you experienced moral distress related to caring for a patient in a critical care unit. A follow-up interview may occur to clarify any questions the investigator had from the interview. The interview will be tape recorded so we are sure to get your ideas, but no name will be recorded on the tape. Approximately 15 registered nurses will be interviewed during the study.

RISKS AND DISCOMFORTS

Sometimes talking about these subjects causes people to become upset. Several questions will ask about things that have happened to you that may have been unpleasant. You do not have to talk about any subjects you do not want to talk about, and you may leave the interview at any time. If you become upset, the study staff will give you names of counselors to contact so you can get help in dealing with these issues.

BENEFITS TO YOU AND OTHERS

You may not get any direct benefit from this study, but, the information we learn from people in this study may help us design better programs for parents and schools.

COSTS

There are no costs for participating in this study other than the time you will spend in the groups and filling out questionnaires.

ALTERNATIVES

The alternative to participation in this research study is not to participate.

APPROVED

11-28-11/LU/JR

[Version 1- 9/25/2011]

CONFIDENTIALITY

Potentially identifiable information about you will consist of demographic data, interview notes, and audiotapes of interviews. Data are being collected only for research purposes. Your data will be identified by ID numbers, not names, and stored separately in a locked research area. All personal identifying information will be kept in password protected files and these files will be destroyed according to the policies and guidelines of Virginia Commonwealth University Office of Research. Other records (audiotapes of interviews) will be kept in a locked file cabinet. Professionally transcribed copies of the interviews will be kept indefinitely. Access to all data will be limited to study personnel.

We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes, or by Virginia Commonwealth University. Personal information about you might be shared with or copied by authorized officials of the Department of Health and Human Services (if applicable).

What we find from this study may be presented at meetings or published in papers, but neither your name nor personally indentifying information will ever be used in these presentations or papers.

If you tell us that you are harming someone, or that you might hurt yourself or someone else, the law says that we have to let people in authority know so they can protect those individuals.

The individual interviews will be audio taped, but no names will be recorded. At the beginning of the interview, each participant will be asked to use initials only so that no names are recorded.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study. If you decide to withdraw from the study there will be no penalty for your decision to do so.

Your participation in this study may be stopped at any time by the study staff without your consent. The reasons might include:

- the study staff thinks it necessary for your health or safety, or
- administrative reasons require you to withdraw.

APPROVED

11-28-11/Lu/JR

[Version 1- 9/25/2011]

QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:

D. Patricia Gray, PhD, Chair, Adult Health and Nursing Systems (Principal Investigator)
 School of Nursing, Virginia Commonwealth University
 1100 E. Leigh Street
 Richmond, VA 23298
 (804) 828-0724

If you have any questions about your rights as a participant in this study, you may contact:

Office for Research
 Virginia Commonwealth University
 800 East Leigh Street, Suite 113
 P.O. Box 980568
 Richmond, VA 23298
 Telephone: 804-827-2157

You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at <http://www.research.vcu.edu/irb/volunteers.htm>.

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.

Participant name printed	Participant signature	Date
Name of Person Conducting Informed Consent Discussion / Witness		
Signature of Person Conducting Informed Consent Discussion / Witness		Date
Principal Investigator Signature (if different from above)		Date

APPROVED11-28-11 / LU / JR

[Version 1- 9/25/2011]



**Participants Needed for Research Study:
“Being Certain” – Moral Distress in Critical Care Nurses**

Are you:

A registered nurse employed in a critical care setting?

Have you ever:

Experienced moral distress while caring for a critically ill patient?

Moral distress is the experience that occurs when a nurse is certain of the right action to take, but is unable to take the right action due to institutional barriers.

If so, you may be eligible to participate in a research study conducted by researchers in the Virginia Commonwealth University School of Nursing. The purpose of this study is to **understand the experience of moral distress in critical care nurses within the practice setting**. Participation involves a confidential interview consisting of answering questions at a mutually agreed upon location. Interviews will be audio-tape recorded. All shared information will be de-identified for confidentiality of participants.

Interview Duration: Approximately 1 hour

For more information regarding this study, please contact Marian Baxter, VCU, School of Nursing at (804) 396-7116, or email mlbaxter@vcu.edu

APPROVED

11-28-11 / LU / JR

9/25/2011

Page 1

“Being certain”: Moral distress in critical care nurses

Recruitment Narrative



Thank-you for contacting me about the research study, “Being certain”: Moral distress in critical care nurses, that is being conducted by researchers from Virginia Commonwealth University (VCU). The purpose of the study is to gain a better understanding of the experience of moral distress in critical care nurses. It will take about five minutes to hear more about this study. May I continue?

If you meet the criteria for the study, you will be invited to participate in a one-hour interview that focuses on your experience of moral distress, defined as the experience that occurs when a nurse is certain about the right action to take, but is unable to take the right action because of institutional barriers. The interviews will be audio-tape recorded. The information you share will not be identified with you. There will be no payment for your participation in the study. Your decision about whether to be in the study or not will not affect your current employment in any way. The criteria for inclusion in the study are:

- Current employment as a registered nurse in a critical care area,
- Having experienced moral distress in the practice setting,
- Ability to speak and understand English.

Do you meet these criteria?

If NO: Thank-you for your call. If you know others who may qualify and who may be interested, I would be grateful if you would tell them about this study and how to contact me.

If YES: Do you have any questions at this point?

If YES: Answer.

APPROVED

11-28-11/Lu /JL

9/25/2011

Page 1

If NO questions: Would you be willing to meet at a location that is convenient to you to provide you with the informed consent document and answer any questions you have? At that time you can complete the informed consent document or take it with you and complete it later. I can also mail the informed consent document to an address of your choosing. Within a week of receiving the document, I will call you or ask you to contact me with any questions. Once you complete the document, please call me to schedule an appointment for the interview.

If Informed Consent to be mailed: To what address or email should I send the informed consent form?

Contact Information: Do you prefer to contact me or may I have your contact email address or phone number to answer any questions and schedule the interview if you decide to participate?

Thank you for your time today. I look forward to speaking with you soon. Please let me know if you have any questions in the mean time. I can be reached at (804) 396-7116 or email mlbaxter@vcu.edu.

APPROVED

11-28-11/Lu/JR

9/25/2011

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Vita

Marian Lynn Baxter was born on May 13, 1955, in Portsmouth, Virginia, and is a citizen of the United States of America. She graduated from Booker T. Washington High School, Norfolk, Virginia in 1973. She received a diploma in nursing from Norfolk General School of Professional Nursing, Norfolk, Virginia in 1976. She received her Bachelor of Science in Nursing from Old Dominion University, Norfolk, Virginia in 1983. She received her Master of Science from Virginia Commonwealth University, Richmond, Virginia in 1985. She also received a Master of Arts in Religious Studies from the University of Virginia, Charlottesville, Virginia in 1993. Her professional positions have included staff nurse, Clinical Nurse Specialist, Director of Nursing, Compliance and Business Integrity Officer, and Integrated Ethics Program Officer. She received a Doctor of Philosophy in Nursing from Virginia Commonwealth University, Richmond, Virginia in 2012.