## EXPLORING HEMATOLOGY ONCOLOGY NURSES EXPERIENCES OF MORAL DISTRESS USING A GROUNDED THEORY APPROACH

#### A DISSERTATION

# SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN THE GRADUATE SCHOOL OF THE TEXAS WOMAN'S UNIVERSITY

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#### **DEDICATION**

To my parents, without them, none of this would indeed be possible.

To the hero nurses in hematology-oncology, for their courage and strength to withstand the most unpredictable challenges and yet being able to provide outstanding patient care.

To my wife Elsa, my children Andrea and Brian, and my friends and colleagues for their encouragement so I could make this long journey.

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#### **ABSTRACT**

#### JOAQUIN BUITRAGO

### EXPLORING HEMATOLOGY ONCOLOGY NURSES EXPERIENCES OF MORAL DISTRESS USING A GROUNDED THEORY APPROACH

#### DECEMBER, 2019

Moral distress is historically defined as occurring when an individual knows the right thing to do, but due to institutional or interpersonal constraints, is unable to do it.

Moral distress is associated with increased burnout and turnover for healthcare professionals and potentially even adverse outcomes for patients, all of which are costly for healthcare systems. Moral distress is most prominent in emergency room, intensive care and oncology nurses, with most studies focused on nurses in the emergency and intensive care settings. While moral distress has been broadly defined for oncology nurses there is a dearth of information specific to hematology-oncology nurses, for whom extended length of stay related to treatment and related toxicities may influence the contributing factors to their experience of moral distress, distinct from those experienced by emergency and intensive care nurses.

This qualitative study applied a Grounded Theory approach to explore hematology-oncology nurses' experience of moral distress. The use of constant comparison techniques within this methodology allowed for exploration and identification of patterns of moral distress in this unique nursing population and relationships between those patterns. These insights informed what contributing factors to

moral distress may be similar to or distinct from those experienced by nurses in other specialties. The identification of these contributing variables informs more robust theoretical models and can guide the development of interventions specific to the hematology-oncology nursing community.

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#### CHAPTER I

#### INTRODUCTION

#### **Focus of Inquiry**

Oncology nurses may delay or avoid voicing ethical concerns while caring for chronically ill patients, perhaps as a result of continually balancing end-of-life, hope, quality of life, and socioeconomic issues (Pavlish, Brown-Saltzman, Fine, & Jakel, 2015). Pavlish et al. (2015a) found that oncology nurses, patients, families, and physicians tend to evade ethical conversations until an imminent crisis arises. The frequent and cumulative exposure to moral uncertainties can prevent oncology nurses from fulfilling their core duty and responsibility to properly care for patients and families (Brint, 2017).

Pavlish et al. (2015a) identified four main factors that impede oncology nurses from expressing ethical concerns while caring for oncology patients. First, the mental and emotional toll in a culture geared towards curing and problem-solving. Second, potential differences in perception of the quality of care may contribute to oncology nurses perceiving the level of caring differently than physicians, and therefore, ethical conversations are viewed at different levels of importance at different times. For instance, oncology nurses may see chemotherapy treatments for critically debilitated patients as more harmful than beneficial to the patients' wellbeing. Third, oncology nurses perceive that engaging in ethical conversations might sometimes disrupt the professional relationship with other healthcare providers, patients, and families. Lastly, oncology

nurses are confronted with medical teams' turnover, such that as physicians change, opinions and beliefs about treatment plans and goals of care may also vary, resulting in barriers to expressing ethical issues and disruption of trust and team relationships (Pavlish et al., 2015a).

Moral distress happens in situations when the ethically appropriate course of action is known but cannot be taken (Jameton, 1984). Exposure to ethical dilemmas is a severe problem among healthcare professionals, particularly nurses who practice in hematology-oncology areas (Neumann et al., 2016). This phenomenon is associated with despair, job dissatisfaction, loss of nurses from the workforce, and the profession as a whole (Bohnenkamp, 2016). According to Johnstone and Hutchinson (2015), moral distress directly affects nurses' job satisfaction, which, in turn, reflects on the quality of patient care and organizations' quality ratings. Quality rankings are measurements of patient and caregiver experience, care coordination, and patient safety reported by the Centers for Medicare and Medicaid Services (2019). Knowing more about the moral distress nurses experience will aid healthcare organizations in ameliorating its adverse effects on nurses, and potentially on patient care outcomes. The purpose of this study was to gain an understanding of the experiences and the contributing factors of moral distress in hematology-oncology nursing.

#### Significance of the Study

Moral distress is a growing problem for healthcare professionals, including oncology nurses, due to the impact of prolonged exposure to ethical dilemmas while caring for both patients and families in times of uncertainties (Tonsing &

Vungkhanching, 2018). These inherent work-related experiences in the oncology setting are associated with continuous interactions with patients and families facing the consequences of life-threatening malignancies, which are exacerbated when they are unable to meet professional and ethical obligations (Johnstone & Hutchinson, 2015). The most prevalent nurses' experiences related to moral distress include inadequate pain management and the inability to stop suffering (Pavlish et al., 2015a). Nurses also face other stressors while caring for patients and families, such as the lack of clear communication between physicians, patients and family members, challenges with informed consent, appropriateness of resuscitation status, the futility of treatments, and truth-telling (Pavlish et al., 2015b).

Constant exposure to ethical and moral stressors has been known to directly affect oncology nursing retention and patient satisfaction (Neumann et al., 2016). One challenge is that these attributes of moral distress have been primarily identified through studies involving nurses in intensive care, emergency, and pediatric settings. While the defined characteristics of moral distress may translate across nurses practicing in diverse health settings, there is a need for further exploration of the potentially unique attributes of moral distress emerging from the hematology oncology nurse population, where the occurrence of moral suffering is high (Corley, 2002).

#### **Rationale for the Study**

Exploration of the processes and progression of moral distress in hematologyoncology nurses will serve to inform whether additional concepts and attributes exist related to the hematology oncology nurse's experience of moral distress, distinct from those experienced by nurses in other fields. For example, moral distress in emergency/trauma nurses stems from the acuity of the cases they treat, including profound trauma from violence, accidents, and sexual assault (Zavotsky & Chan, 2016). In pediatric nursing, moral distress often emerges from the duress of treating children with terminal diseases or traumatic injury (Dos Santos, Garros, & Carnevale, 2018). In critical care, moral distress can appear from the prolongation of life that seems incompatible with the underlying diagnosis (Choe, Kang, & Park, 2015). In palliative care, moral distress can emerge from challenges in managing the pain and suffering of the dying patient (Wolf, 2016). While hematology-oncology nurses may experience moral difficulty related to similar attributes, there may be other attributes, including duration and intimacy of care provided, that influence the occurrence of moral distress in this professional population.

Advances in medicine and cancer research provide more treatment opportunities for hematology-oncology patients (American Society of Hematology, 2019). In their research agenda, The American Society of Hematology (2019), published that current emerging treatments provide the highest potential to manage and cure hematology malignancies. Subsequently, nurses practicing in these areas may face increased challenges, including high acuity patients, newer adverse effects related to treatments, emerging technologies, and monitoring instruments in the areas of precision medicine, epigenetics, gene therapies, immunotherapy, and regenerative medicine (American Society of Hematology, 2019). To be able to care for patients in the context of these new and emerging scientific advances, nurses must maintain competency in different

oncology specialties to be able to overcome moral and ethical dilemmas and ensure the quality of care (Esplen, Wong, Green, Richards, & Li, 2018). The Oncology Nursing Society (ONS), a specialty nursing organization composed of more than 39,000 members representing over 40 countries, includes in its position statement that as complexities of patient care continues to evolve, oncology nurses must uphold proficiency in their areas of specialty for potential cancer prevention, improved quality of life, and provide quality cancer care across the cancer trajectory (ONS, 2019). Concerns about the stressors in which oncology nurses practice have resulted in numerous publications related to burnout, compassion fatigue, secondary traumatic stress disorders, nurse grief, and moral distress (Wahlberg, Nirenberg, & Capezuti, 2016).

Work environments where nurses experience empowerment to practice to their fullest potential and can to advocate for their patients and families are associated with increased nurse retention, recruitment, and job satisfaction. There is decreased stress and burnout, which subsequently results in safer patient practices (Wang & Liu, 2015). ONS (2019) recognizes that oncology nurses practice in fast-paced, challenging clinical environments, and acknowledge the stressors associated with cancer care that can lead nurses to risk their well-being while attempting to provide high a level of quality care to the oncology patients. Sirilla (2014) reiterated that hematology oncology nurse practice is a highly charged, challenging environment within which individual coping response is at stake. Some of the challenges that hematology-oncology nurses need to manage consistently include staffing ratios, various levels of patient acuities, mandatory overtime, and the devastation of the cancer diagnosis for patients and families. ONS addressed

these challenges across multiple position statements in their publications (2019). Moral distress experiences are commonly preceded by frustration, anger, fear, sorrow, low self-esteem, sadness, and helplessness (Ameri, Safavibayatneed, & Kavousi, 2016; Wang, & Liu, 2015; Wahlberg, et al., 2016). Sirilla (2014) has noted the long-lasting effects of moral distress, where the devastating sequels have the potential to affect nurses' wellbeing, quality of patient care, job satisfaction, and career abandonment.

#### **Research Questions**

To better understand and explore the processes hematology-oncology nurses use when experiencing moral distress; the following research questions guided the study:

- How do hematology-oncology nurses experience moral distress?
- What do hematology-oncology nurses perceive as supports and barriers to resolving the experience of moral distress?
- What do hematology-oncology nurses do to improve the experience of moral distress?

#### **Philosophical Underpinnings**

This qualitative study was conducted using the classic grounded theory methodology based on the works of Glaser and Strauss (1967). Pragmatism, combined with symbolic interactionism underpins the ability of grounded theory to aid in identifying what is essential to people, what is problematic, and the process of events or actions implemented to achieve resolution. Pragmatism brings out the ever-changing process of behavior or action patterns in response to problematic situations. People respond to their beliefs as rules for actions, and the ideas produced as their perception of

truth (Corbin & Strauss, 2008). Symbolic interaction influences how people think about themselves and how and why they behave as they do according to learning experiences, beliefs, values, and the environment. These experiences define the perceived truth according to their interpreted meaning of objects, people, ideas, and virtues as symbols (Glaser & Strauss, 1967).

The absence of defined processes in which hematology-oncology nurses confront moral distress and the methods used when attempting to solve the experience offers an opportunity to use the grounded theory research approach (Stern & Porr, 2011). The grounded theory method directs the researcher to examine the underlying circumstances and dimensions of the resultant consequences to explain how participants adapt and cope with their experiences (Corbin & Strauss, 2008). Glaser and Strauss (1967) advocated that the grounded theorist should assume an objective stance and try to get as close to the participants' explanation as humanly possible. In this study, interviewing hematology-oncology nurses was the primary method of data collection to stimulate meaningful conversations that will translate participants' experiences into data. This data was then analyzed to explicate the processes used by hematology-oncology nurses when encountering moral distress events.

#### **Summary**

Exploring moral distress experiences in hematology-oncology nurses provided the opportunity to elucidate the processes nurses use when experiencing ethical dilemmas in their practice. These included uncovering unique characteristics in the environment that exacerbated the experience, as well as methods and obstacles hematology-oncology

nurses faced when attempting to resolve moral distress. Quantitative studies have used the Moral Distress Scale (MDS) to measure the intensity and frequency of this phenomenon in diverse nursing communities (Corley, 2002; Trotochaud, Coleman, Krawiecki, & Cracken, 2015; Wolf, 2016; Zavotsky & Chan, 2016). The lack of foundational research on the potentially unique contributors to moral distress in the hematology-oncology nurse, necessitated additional qualitative exploration of this phenomenon in this population to explicate the existing theoretical framework further. Since the processes in which hematology-oncology nurses experience and attempt to resolve moral distress have not been previously studied, and the potential for this phenomenon appears to be high for those nurses, it was of great importance to explore those processes. The expanded knowledge about moral distress gained in this study provided direction to nursing research, education, and practice specific to hematology-oncology nurses.

#### CHAPTER II

#### MORAL DISTRESS IN ONCOLOGY NURSING: AN INTEGRATIVE REVIEW

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#### **ABSTRACT**

**Aim:** The purpose of this literature review is to examine and describe the literature focused on moral distress experienced by oncology nurses.

**Background:** Moral distress is a phenomenon in which a nurse discerns the morally right course of action to take in a given situation, but institutional interprofessional barriers create obstacles that are in contradiction to that action. The accumulative effect of moral distress leads to despair, low performance, and job dissatisfaction. Within the specialty of hematology-oncology nursing practice, moral distress may negatively affect retention and patient satisfaction.

**Methods:** The integrative review of the literature followed strategies delineated by Whittemore and Knafl (2005). Electronic databases, including EBSCOhost, CINAHL, PsycINFO, PubMed, and Cochrane, were accessed to review the literature from 1984 to 2019.

**Conclusion:** Moral distress represents a barrier for the oncology nurse while caring for patients undergoing malignancy treatments. There are clinical and environmental factors causing moral distress affecting nurses practicing in this setting.

Implications for nursing management: This study will assist nurse leaders to understand the possible sources and consequences of moral distress in oncology nursing. Nurse leaders are in key positions to anticipate and mitigate morally distressing events that may negatively affect both staff and patient outcomes.

#### **Keywords**

Moral distress, oncology nursing, intention to leave, work environment, literature review

#### Introduction

Moral distress is caused by situations in which the morally appropriate course of action is known but cannot be taken. Jameton (1984), the pioneer of the concept of moral distress, described the concept as "a phenomenon in which a nurse knows the morally right course of action to take, but institutional structure and workers create obstacles to accomplish these actions" (p. 6). The Oncology Nursing Society (2019) recognizes that moral distress affects nurses' physically, psychologically, and socially, resulting in lower quality of patient care and patient dissatisfaction. Although this experience is not unique to nursing, oncology nurses often feel unable to assert ethically appropriate actions that may cause moral constraint, moral conflict, or both (Fourie, 2015). As a result, nurses report experiencing powerlessness when unable to properly care for patients and families under these circumstances (Borhani, Abbaszadeh, Nakhaee, & Roshanzadeh, 2014).

This paper presents the findings of a review of the literature regarding moral distress in oncology nursing. Understanding the causes leading to moral distress may lend value for nurse leaders to address these issues and remediate the experience. Providing proper resources may improve job satisfaction, nursing retention, and quality of patient care.

#### **Background**

The attributes of moral distress have been primarily identified through studies involving nurses in the emergency, pediatric, school, intensive care, and palliative settings. While the identified attributes of moral distress may translate across nurses practicing in diverse health settings, there is a need for further exploration of the

potentially unique attributes of moral distress emerging from the oncology nurse population, where the occurrence of moral distress is high (Corley, 2002).

In emergency and trauma nursing, moral distress stems from caring for patients in a fast-paced environment where treatment can be intense and unpredictable. The most common disturbances were working with unsafe staff, witnessing poor team communication, assisting incompetent physicians and nurses, initiating lifesaving measures to prolong death, following family wishes to not discuss death, and limited resources (Wolf, 2016; Zavotsky & Chan, 2016).

In pediatric nursing, moral distress often emerges from the duress of treating terminal disease or traumatic injury in children. The main causes of moral distress recorded in the literature include providing unnecessary futile treatment, inadequate communication between team members, inadequate patient informed consent, insufficient number of professionals, and increased workload. Other identified sources included, working with professionals who are not competent, policies and priorities conflicting with care needs, following the wishes of family members for fear of legal proceedings, providing inadequate pain relief, accelerating the death process, nurses not involved in the decision-making process, commitment to care due to fear of legal proceedings, and disregarding the wishes of the patient. (Dos Santos, Garros, & Carnevale, 2018; Kruse, Batten, Constantine, Kache, & Magnus, 2017).

In school nursing, moral distress may arise from conflicts between their organizational and professional obligations. The sources of moral distress among nurses in this setting varies, the most common reasons reported include the inability to provide

care due to lack of time, and workload, unable to achieve goals due to students' family situations, and limited private space to work with students (Powell, Engelke, & Swanson, 2018). The experience of moral distress exacerbated in this setting by feeling unable to advocate and promote the wellbeing of the students, in particular, those with special needs and chronic conditions (Powell, et al., 2018).

In the intensive care unit (ICU), nurses experience moral distress related to the incongruences in the plan of care for critically ill patients and their families. The most common factors reported of moral distress in the ICU included concerns about care provided by other health care professionals, too much life-support at the end of life, poor communication among healthcare professionals and patients, aggressive treatments and decision-making at the end-of-life, insufficient staff, excessive documentation requirements that compromise patient care, lack of resources, and witnessing health care providers giving "false hope" to a patient or family (Dodek, Norena, Ayas, & Wong, 2019; Epstein, Whitehead, Prompahakul, Thacker, & Hamric, 2019).

In palliative care, moral distress can emerge from challenges in ameliorating the pain and suffering of the dying patient. Vague and unclear communication from healthcare providers about patients' condition and prognosis sparked moral distress in nurses. Also, the perceived lack of collaboration among health care professionals or the perceived decisions that are not in the patient's best interest for the patient, and the inability to stop suffering at the end-of-life aggravates the experience (Mehlis et al., 2018; Young, Froggatt, & Brearley, 2017; Wolf, 2016). Further, conflicting emotions result in cases where aggressive care is rendered, denying palliative care, and situations

when refraining from resuscitation during a cardiac and respiratory arrest does not appear to be the morally appropriate action to be taken.

#### **Theoretical Foundation**

Corley (2002) introduced the moral distress theory, which consists of both moral concepts that contribute to moral distress, as well as potential outcomes resulting from these concepts. A distressing situation can result in either the moral intent to act on the situation in order to achieve moral comfort or in moral distress, suffering, or residue, which can have consequences for the patient, nurse, and organization (Corley, 2002). Despite the well-defined concepts and sequelae of moral distress presented in this theoretical model, Corley acknowledges that "factors predicting moral distress have not been identified [and] inconsistent findings among researchers on the leading sources of moral distress may reflect different work settings and times" (p. 648). These situations are particularly true for oncology nurses, with whom there is an opportunity to further elucidate sources of and contributing factors to their experience of moral distress. Exploration of this phenomenon in this population further explicates the existing theoretical framework.

#### Aim

The purpose of this review was to synthesize the evidence about moral distress experienced by oncology nurses.

#### Design

The review of the literature followed the strategies delineated by Whittemore and Knafl (2005). The framework for the integrative review included problem formulation, literature search, data evaluation, data analysis, and synthesis of the findings.

#### Search

The academic databases EBSCOhost, CINAHL, PsycINFO, PubMed, and Cochrane Library, were searched for research studies published between 1984 and 2019. The initial time parameter was selected based on the first publication of the concept of moral distress by Jameton (1984). Search terms used were moral distress, moral burden, moral problems, and moral conflict, combined with hematology and or oncology nursing. Reference lists in the articles were searched to identify any additional publications. Editorials, commentaries, case studies, dissertations, book chapters, and letters were excluded.

Inclusion criteria were (a) Jameton's concept of moral distress, (b) English language, and (c) the population was oncology nursing. The preferred reporting items for systematic review and meta-analysis PRISMA (Moher, Liberati, Tetzlaff, & Altman, 2009) was used to record the literature search process. The electronic databases originally provided 2,028 articles. After initial screening, 1,307 articles were rejected because their topics were non-oncology nursing, student nursing, or commentary papers. Twenty-three articles were duplicate publications, and 139 additional articles were excluded as these did not meet the inclusion criteria. Eleven articles were selected for review (see Figure 2).

#### **Qualitative Appraisal**

The advancing research and clinical practice model was used to assess the methodological strength of the evidence (Melnyk & Fineout-Overholt, 2019). The strength of evidence among the studies varies and is consistent with level IV single (n = 1) correlational observational study, and level VI (n = 10) single descriptive or qualitative study. Following Noyes and Popay's (2007) recommendation, all articles were analyzed regardless of appraisal quality to identify any substantial evidence of moral distress in weaker articles.

#### **Data Appraisal**

The primary data analysis systematically compared and synthesized primary sources of moral distress studies in oncology nursing. All studies applied analysis methods appropriate to the research design, statistical analysis in quantitative studies (n = 4), and different analysis methods applicable to qualitative research data (n = 7) were used for analysis. The extracted data were coded and then compared; similar data were categorized and grouped using an Excel spreadsheet.

#### **Results**

#### **Characteristics of the studies**

The data extracted from the reviewed studies are displayed in a methodologic matrix (see Figure 1). Of the 11 studies, five were conducted in the US, two in Brazil, one in Belgium, Italy, India, and Tehran, respectively. There were studies reporting evidence from descriptive analyses (n = 8), cross-section analysis identifying relationships of data with participants' demographics (n = 3), and ethnography

methodology (n = 1). Sample sizes ranged from 18 to 279 for a total sample of 1,185. See Table 1 for a summary of the reviewed studies.

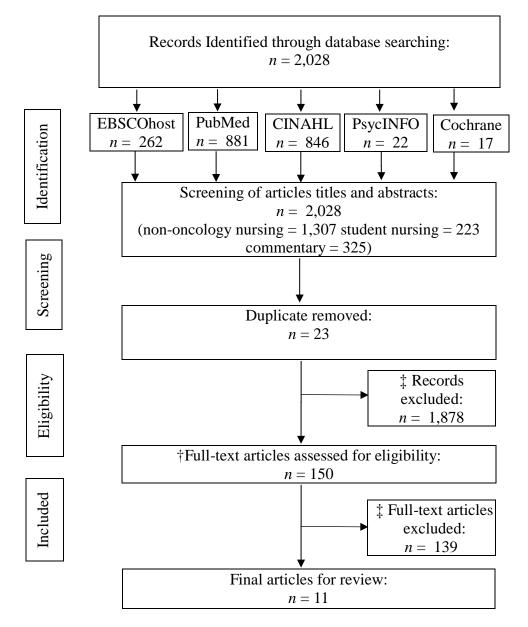


Figure 1. Flowchart of the study selection procedure representing the method for selecting articles from electronic databases. † Only articles addressing moral distress and Jameton within a nursing context included. ‡ Only argument-based articles with a clear

focus on the concept of moral distress included: no, editorials, commentaries, theses, book chapters, and conference proceedings.

#### **Sources of Moral Distress**

Unanimously throughout the literature, the most common causes of moral distress in oncology nursing can be classified into two areas, clinical situations, and work environment-related events. Wilkinson (1987) described moral stressors in clinical situations as those events perceived as decreasing the ability to provide care in the clinical context. Nurses more often reported cases concerned with aggressive and heroic treatments for patients at the end-of-life, performing unnecessary tests and treatments on terminally ill patients, perceived lying or no clear explanation of treatment, and perceived incompetent nurse or physician was caring for oncology patients. Lake (2002) defined work environment moral events as "the organizational characteristics of a work setting that facilitate or constrain professional nursing practice" (p. 178). Work-environment related moral stressors included feeling overworked, not able to advocate for patients due to fear of organizational retaliations, institutional policies that required cost controls, inadequate staffing, and perceived ineffective bioethical and legal policies that could negatively affect patient care (Corley, Elswick, & Jacobs, 2005).

#### **Clinical situations**

**Futile treatments.** Bohnenkamp, Pelton, Reed, and Rishel (2015) explored the sources of moral distress in an oncology surgical unit in a National Institute of Health designated cancer institution in the United States. Results showed a high incidence of moral distress in nurses when providing care that was perceived as not in the best interest

of the patient. Ameri, Safavibayatneed, and Kavousi (2016) identified that one of the highest sources of morally distressful situations arose from perceived futile care when the aggressive treatments were perceived as harmful and carrying out the physicians' orders for what they considered were unnecessary tests and treatments. Da Luz et al. (2015) reported nurses feeling disturbed when administering perceived aggressive treatments that were not compatible with patients' expectations, or when sedation at the end-of-life became uncertain treatment because there was no consensus among the patients, families, and nursing staff.

Rice, Rady, Hamrick, Verheijde, and Pendergast (2008) presented high turnover nursing staff and low scores in patient satisfaction ratings in the oncology surgical unit. Intention to leave or change nursing roles was found to be highly correlated with perceived futile treatments. The situation was exacerbated in the presence of aggressive treatments at end-of-life or in the presence of end-stage organ failure patients (Rice et al., 2008). Nurses reported a high incidence of moral distress events in the presence of perceived aggressive treatments to patients with poor prognosis or advanced illness. Pavlish, Hellyer, Brown-Saltzman, Miers, and Squire (2015) identified similar causes of moral distress in oncology nurses when caring for patients at the end-of-life with perceived aggressive treatments (N = 28) from two oncology centers in the US.

Unable to stop suffering. Prolonging patients' pain and suffering due to inadequate medication management, inability to control pain, and suffering (Rice et al., 2008). Ameri et al. (2016) reported one of the most intense experiences of moral distress occurred when providing care that did not relieve suffering because physicians feared

increasing the dose of pain medication might cause death. Da Luz et al. (2015) identified moral distress experienced by oncology nurses in a hospital in Brazil. Participants described feeling devastated when unable to relieve pain and suffering. While validating the Moral Distress Scale (MDS) instrument, Lazzarin, Biondi, and Di Mauro (2012) identified the most frequent causes of moral distress in pediatric oncology nursing related to inefficient pain management and care of the pediatric patient and family at the end-of-life. Internal consistency reliability using Cronbach's coefficient alpha for each item suggested relative high internal consistency ( $\alpha$  = 0.959), the intensity ( $\alpha$  = 0.967), and frequency ( $\alpha$  = 0.95) of the adapted instrument. There were a number of research studies suggesting that poor ethical climate in the oncology setting negatively impacted caring values and ideals when unable to stop patients' suffering (Ameri et al., 2016; Bohnenkamp et al., 2015; Da Luz et al., 2015; Lazzarin et al., 2012; LeBaron, Beck, Black, & Palat, 2014; Rice et al., 2008).

Unclear communication. Da Luz et al. (2015) described problematic communication, including conflicting messages from different physicians about symptoms. For example, one physician was surprised about the patient's results, while others said it was normal. Unclear health information explained to patients and families contributed to nursing moral distress identified as disrespect for the patient's autonomy. Absence or no clear information about treatments, cancer-related diagnosis and prognosis, incomplete health records, and recognition of unpreparedness exacerbated the experience (Da Luz et al., 2015). Often the morally distressing situations in oncology nursing involved problems related to the inability to get clear answers to patients' queries

about complications they were experiencing, poor nurse to physician communication, and perceived violation of patients' advance directives (Ameri et al., 2016; Bohnenkamp et al., 2015; Da Luz et al., 2015; Lazzarin et al., 2012; LeBaron et al., 2014; Pavlish et al., 2015; Rice et al., 2008; Sirilla, 2014).

#### Work-environment

Insufficient staffing. In a descriptive exploratory study using a 15-item Likert-type scale instrument, Bohnenkamp et al. (2015) explored the sources of moral distress in an oncology surgical unit. Among all nurses (n = 41) with a 41% response (n = 19), the result showed that the most frequent events of moral distress in oncology nursing derived from working with unsafe staffing levels. Turnover has also been identified in the literature to contribute to moral distress, patient quality of care, and satisfaction at work. Dissatisfied nurses tend to leave the oncology setting. Thus, dissatisfaction can be a factor that generates poor quality of care, change work setting, and change nursing specialty (Bohnenkamp et al., 2015; Dyo, Kalowes, & Devries, 2016; LeBaron et al., 2014).

Incompetency. Perceived incompetence of nurses and physicians was a source of considerable moral distress, particularly when deemed to threaten the integrity of the patient. Insufficient knowledge, unpreparedness, and inexperience were identified as causing the most distressing experience of moral distress when working with nurses or other healthcare providers who they perceived as incompetent to meet the patient care requirements (Ameri et al., 2016; Bohnenkamp et al., 2015; Da Luz et al., 2015; Dyo et al., 2016; Fruet et al., 2017; Pavlish et al., 2015b; Rice et al., 2008). Pavlish et al. (2015b)

also identified a source of moral distress, working with health care providers experiencing moral distress.

Limited resources. Five studies explored the psychological responses to working with limited resources to provide patient care. Feelings of frustration and moral distress were present in situations of improvisation when the resources necessary to deliver integral care were unavailable. The lack of organization in the work environment concerning insufficient material resources generated feelings of worry, helplessness, despair, guilt, among others. (Bohnenkamp et al., 2015; Da Luz et al., 2015; Fruet et al., 2017; Pavlish et al., 2015; Rice et al., 2008). While investigating a potential relationship of moral distress and opioid availability for cancer pain management, LeBaron et al. (2014) concluded the presence of work-related moral distress in oncology-related to a lack of basic supplies to care for their patients. For instance, the limited available bedpans, thermometers, and protective equipment were reported as a barrier for nurses to care for patients properly.

Unable to advocate. The inability to advocate for patients and feelings of powerless to influence their wellbeing also contributed to moral distress. LeBaron et al. (2014) indicated that oncology nurses felt helplessness and powerlessness when they could not do the right thing and unable to influence the care decisions of their patients. A sense of powerlessness was expressed within the context of a perceived power differential that tips unfavorably for the patient creating a sense of hopelessness frustration, guilt, and anger (Bohnenkamp et al., 2015; Da Luz et al., 2015; Lazzarin et al., 2012; Lievrouw et al., 2016; Rice et al., 2008). Nurses' inability to influence patient

situations contributed to moral distress (Fruet et al., 2017). LeBaron et al. (2014) indicated that oncology nurses felt a strong sense of helplessness and powerlessness when facing moral and unethical events.

Lack of leadership support. LeBaron et al. (2014) identified lack of support from nursing leadership creates an undesired environment where oncology nurses reported staff favoritism, lack of leadership involvement in patient care issues, lack of training, and fear of disciplinary action for not following orders or being blamed for bad outcomes. The perceived absence of supervisor figure in many instances was reported as a factor for moral distress in oncology nurses (Bohnenkamp et al., 2015; Lazzarin et al., 2012; Sirilla, 2014). Participants reported that on occasions when managers' responses to clinical and administrative critical events are perceived as inappropriate or ineffective, exacerbate the moral distress experienced.

#### **Predictors of Moral Distress**

Nurses' demographics and practice environment were influential predictors of the frequency and intensity of moral distress.

**Demographic factors.** Ameri et al. (2016) identified that the higher the oncology experience, the lower the moral distress scores (p = 0.01, r = 0.24). Rice et al. (2008) found that nurses employed for more than three years and those with more than six years of experience reported higher levels of intensity of moral distress when dealing with perceived futile treatment and transparency. Fruet et al. (2017) identified that the perception of distressful moral events increased in nurses working in oncology for more

than five years, in particular, experiences related to unable to advocate for patients and families (Fruet et al., 2017).

Inconsistent findings were found with regard to age and level of nursing education. Rice et al. (2008) reported nurses aged 34 years or older were associated with a higher incidence of moral distress in the presence of perceived futile care. Sirilla (2014), however, did find a statistically inverse relationship. Nurses with higher levels of education tend to experience less moral distress than those with lower levels of education (p = 0.22). Fruet et al. (2017) identified that nurses with postgraduate degrees and participated in medical team dialogues presented a higher incidence of moral distress related to patient's autonomy. In the pediatric oncology setting, the correlation between the moral distress score, age, years of nursing experience, and years of pediatric oncology or hematology were not significant (p > 0.05), while there was a significant moral distress correlation among full-time and part-time nurses (p < 0.05). Full-time nurses obtained higher MDS scores than those working part-time (Lazzarin et al., 2012).

**Practice environment.** Sirilla (2014) identified a correlation between the type of unit and the moral distress score. Nurses working in surgical oncology units reported higher levels of moral distress compared to those working in the bone marrow transplant units (p = 0.03). Sirilla also found that 22 of the 73 participants (30%) considered leaving their position as a result of the feeling of frustration, dissatisfaction, and ultimately, moral distress experiences. Five of the respondents reported leaving their previous positions due to moral distress experiences.

# **Collective Meaning of Moral Distress in Oncology Nursing**

Moral distress for the oncology nurse can be defined as the psychological tension caused when the core values of caring for patients and families undergoing cancer treatment are threatened (Bohnenkamp et al., 2015; Lazzarin et al., 2012; Da Luz et al., 2015; LeBaron et al., 2014; Sirilla, 2014). LeBaron et al. (2014) indicated that oncology nurses felt a strong sense of helplessness and powerlessness when facing moral and unethical events. Nurses who are experiencing moral distress withdraw or distance themselves from patients and their families.

Throughout the literature review, researchers identified the psychological, physical, and social effects of moral distress in oncology nursing. The most common psychological effects reported were feeling of hopelessness frustration, guilt, anger, and powerlessness (Bohnenkamp et al., 2015; Lazzarin et al., 2012; LeBaron et al., 2014; Lievrouw et al., 2016; Da Luz et al., 2015; Rice et al., 2008). In some cases, the participants could recall the distressing experience in detail regardless of the elapsed time since the experience occurred (Lievrouw et al., 2016). Physical effects identified included headache, neck, muscle, and stomach pain, as well as sleep disturbances (LeBaron et al., 2014). The social effects included constantly expressing their feelings and concerns to family, friends, and colleagues in their quest for support. However, researchers indicated that the unresolved effects of the phenomenon resulted in changing job positions, reluctance to return to work, and in some cases, distancing themselves from patient care (Lazzarin et al., 2012; LeBaron et al., 2014; Rice et al., 2008; Sirilla, 2014). Rice et al. (2008) and LeBaron et al. (2014) described that exposure to moral distressing situations

might have a cumulative effect, commonly described as a crescendo effect, which may increase the likelihood of nurses leaving the clinical setting. Nurses who are experiencing moral distress withdraw or distance themselves from patients and their families.

#### Limitations

This integrative review has brought a glimpse into the experiences of moral distress in oncology nursing from international studies. Results from these studies may suggest similitudes in the experiences under clinical and workplace environment perspective; however, only one study compared the experiences across different oncology specialties, which may prevent to establish generalizability of results with certainty. The nonexperimental studies included in the final analysis cannot assert causal relationships. For example, it is not known whether implementing ethics interventions will alleviate moral distress experience among oncology nurses.

#### Discussion

The literature review was conducted to synthesize the evidence of moral distress in oncology nursing and to refine the design of future studies. The findings presented suggested that moral distress in oncology nursing impacts advocacy for the wellbeing of the patients undergoing treatment. The research studies suggested that poor ethical climate in the oncology setting negatively affects the nursing practice and patient care (Ameri et al., 2016; Bohnenkamp et al., 2015; Da Luz et al., 2015; Lazzarin et al., 2012; LeBaron et al., 2014; Rice et al., 2008). The findings of this review can be compared with previous research in which nurses' reported an inability to promote patients' wellbeing and stop suffering contributed to the moral distress experienced (Wolf, 2016).

The collective meaning of moral distress in the studies can thus be associated with restraining advocacy for the oncology nurse. The perceived restraints of the relationship between nurses and patients and the perceived unclear communications related to medical treatments and prognosis represented disturbing moral and ethical events. Jameton's (1984) definition of moral distress is synthesized throughout the studies as the process in which the nurses face moral challenges to overcome organizational barriers while caring for patients.

The association between demographic variables and frequency and intensity of moral distress are inconsistent through the studies. Hence, some evidence suggests congruence regarding the relationship between years of oncology experience, education, and age variables, and moral distress. Incongruences in demographics findings might be due to differences in cultures and settings — for instance, the country of the study and oncology specialty units. Also, years of experience could affect how nurses addressed ethical problems that arose in clinical practice. Older nurses may have learned to cope with moral distress. Although demographic factors were not significant predictors of moral distress, Epstein, Whitehead, Prompahakul, Thacker, and Hamric (2019) explained that some demographic variables did predict the experience. Furthermore, the level of distressing events tended to decrease as the years of nursing profession and education increase (Epstein et al., 2019).

Clinical situations continued to influence the moral distress experienced. Futile treatments and unclear communication contribute to the frequency and intensity of moral distress (Wilkinson, 1987; Corley et al., 2005). Moral distress must be addressed by

multiple contexts such as clinical and work-environment perspectives with the purpose of support ethical issues in nursing practice. In the work-environment context, staffing issues, limited resources, unable to advocate for patients, and ineffective leadership represented key issues for the oncology nurse (Ameri et al., 2016; Bohnenkamp et al., 2015; Da Luz et al., 2015; Dyo et al., 2016; Fruet et al., 2017; Pavlish et al., 2015b; Rice et al., 2008). Nurse leaders are in key positions for reallocating resources and enhancing nursing staff support in their practice. These findings are supported by previous literature reviews, insufficient staffing and resources, poor communication, lack of leadership involvement, and a negative ethical climate that can exacerbate ethical situations (Oh & Gastmans, 2015).

The repetitive exposure to moral distress gradually raised moral residue, and the intensity of the experience may have a long-lasting effect on oncology nurses (Corley, 2002). Furthermore, the intensity and frequency of exposure of the events exacerbated the morally disturbing experiences, building-up to a moral crescendo and emotional exhaustion (Musto, Rodney, & Vanderheide, 2015). The accumulative effect of moral distress can lead to despair, low performance, and dissatisfaction in oncology nursing practice, and the environment under these conditions can contribute to changing jobs, patient outcomes, and dissatisfaction with the profession as a whole (Wolf, 2016).

The appraisal of the articles in this review suggested that improving the oncology nursing work environment might assist in increasing job satisfaction and retention rate.

The impact of this knowledge may assist nurse leaders in recognizing possible sources, and the effects of moral distress in oncology nurses that appear to affect nursing staff

negatively. Leadership presence is worthy of engaging in clinical practice to formulate supportive interventions for clinical nurses. Allocating proper resources and making necessary adjustments in organizational factors are necessary to address nursing retention and improve patient quality of care (see Figure 2).

- Moral distress in oncology nurses is associated with despair, job dissatisfaction, and loss of nurses from the workforce.
- The most prevalent reported factors of morally distressful situations included futile treatment, unable to stop suffering, lack of clear communication, insufficient staffing, perceived incompetent staff, insufficient resources, powerlessness, and lack of leadership support.
- Key components to ameliorate moral distress in oncology nursing practice includes supportive resources: safe staffing levels, nursing leadership involvement, and allocation of resources to support nursing practice.
- There is a need to develop nursing interventions to help improve oncology nurses' ability to overcome obstacles when attempting to resolve moral distress in the oncology setting.

Figure 2. Key points for policy development, nursing practice support, and future research initiatives to support nurses minimizing the effects of moral distress events.

## Conclusion

This study indicates that the hospital's ethical climate is important in nurses' decisions to leave their positions and to leave the profession. People concerned with nursing retention should consider this important variable in nurses' turnover intentions. Improvements in nursing retention might also be achieved when nurses can maintain control over their professional nursing practice, and when employers address nurses' concerns regarding workload and staffing. Retention strategies should address issues

directly affecting oncology nursing practice, such as patient acuity, safe staffing, resources, and leadership support.

This integrative review explored a variety of studies that examined moral distress assessed in the oncology setting. Moral distress signifies a barrier for the oncology nurse who serves as a caring agent advocating for the wellbeing of the patient. The reasons for nurses' intention to leave oncology and the profession are complex, and clinical and work-environment related factors influence them. Although there was ample research describing the experiences, sources, and consequences of moral distress in oncology nursing, there are inconsistencies when correlating the experience with nurse demographics and work environment.

This review constitutes a crucial point for future research. In fact, even as we are able to conceptualize this phenomenon and better understand its sources and consequences, there are areas remained to elucidate, in particular with regard to the factors that may be exclusive to nurses in different oncology settings. Another relevant subject of study would be how nurses in different oncology areas deal with moral distress situations, the resources and processes they use to manage the experience, and with whom they seek assistance in situations where decisions must be made on ethical and moral grounds. In everyday nursing practice, these aspects are far from trivial. Finally, in as much as this review is a compilation of articles from various sources, it is international in nature. This said, it would be premature to assume that moral distress in oncology nursing is uniform, regardless of where it is practiced. This finding appeared relevant for

nurse leaders who may periodically monitor the emotional status of the staff while caring for oncology patients.

Table 1
Summary of Studies Included in the Integrative Literature Review

Author	Purpose	Design / setting	Level evidence	Instrument	Sample		Findings	
						Sources of moral distress	Outcomes	Predictors
Ameri et al. (2016)	Evaluate the intensity and frequency of moral distress and relationship between moral distress and demographic characteristics of oncology nurses	Descriptive analysis. Oncology units in training hospitals (n = 8) in Tehran	VI	MDS- Revised	N = 148 oncology nurses	<ul> <li>Futile care</li> <li>Unnecessary test and treatments</li> <li>Inadequate pain management</li> <li>Work with nurses or other healthcare providers who are not as competent as patient care requires</li> <li>Provide less than optimal care due to pressure from administrators to reduce cost</li> <li>Be required to care for patients I do not feel qualified for</li> <li>Absence of patient informed consent for treatments.</li> </ul>	<ul> <li>Highest frequency and intensity of moral distress related to failure to provide informed consent.</li> <li>Futile treatments</li> <li>Hopelessness</li> <li>Despair</li> </ul>	Demographics show a relationship between the higher oncology experiences, the lower the moral distress scores.

Bohnen kamp et al. (2015)	Describe how an inpatient nursing team addressed ethical concerns and problems that occurred in a surgical oncology unit.	Descriptive exploratory Oncology unit in a teaching hospital in the US	VII	15-item moral distress clinical survey	N = 19 Oncology nurses	<ul> <li>Working with unsafe staffing levels</li> <li>Working with an incompetent doctor</li> <li>Pain medication orders that do not alleviate pain</li> <li>Orders that are not in the best interest of the patient</li> <li>Working with a nurse who provides incompetent care</li> </ul>	<ul> <li>Significant turnover of nursing staff</li> <li>Low nursing performance</li> <li>Low quality of care</li> </ul>	not reported
Da Luz et al. (2015)	To know the ethical problems experienced by oncology nurses	Descriptive /explorator y study with qualitative approach. Brazil	VI	Semi- structured interviews	N = 18 Oncology nurses	<ul> <li>Lack of clear information to patients and caregivers</li> <li>Unable to control suffering at the endof-life</li> <li>Incomplete or absence medical records</li> <li>Imposed limitation to advocate for patients</li> <li>Lack of materials and resources</li> </ul>	• Low quality of care • Powerless	not reported

<ul> <li>Family members opposed to talking about poor prognosis with the patient</li> <li>Dealing with patients whose caregivers were trying to cross the border before patients pass away</li> <li>Low levels of staffing</li> <li>Feeling unsafe due to hostile patients or families.</li> <li>Critical care nurses had the highest levels of moral distress, intensity, and frequency.</li> <li>Adult units had significantly higher levels of moral distress than pediatrics and neonatal units</li> <li>There was no significant difference when comparing age, education, or years of experience, both frequency and intensity.</li> <li>Moral distress</li> </ul>
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Fruet et al. (2017)	To verify the applicability of the adapted Moral Distress Scale in the nursing setting of the hemato-oncology sector of a university hospital	Cross- sectional survey. Brazil	IV	MDS	N = 23 Hem / Oncology nurses	<ul> <li>Lack of competence in the work team</li> <li>Disrespect for the patient's autonomy</li> <li>Denial of the nursing role as a patient's advocate by other healthcare professionals.</li> </ul>	• Nurses in oncology, palliative, neonatal, adult intensive care units, and emergency services seem to be more susceptible to moral distress. • Feelings of impotence, frustration, guilt, and fear of losing their job.	• Nurses working longer than five years in oncology was associated with a higher perception of moral distress • Nurses with higher education had a higher incidence of moral distress
Lazzarin et al. (2012)	Translate the pediatric version of the MDS-PV to the Italian language	Descriptive correlation hospitals ( <i>n</i> = 6) in Italy	VI	MDS- Pediatrics Version	N = 182 Pediatrics Hem/onc ology nurses	<ul> <li>Lack of time</li> <li>Supervisory</li> <li>disinterest</li> <li>Medical power</li> <li>Institution policy</li> <li>Legal limits</li> <li>Lack of expertise</li> <li>and protection of the minor's privacy.</li> <li>Working with levels of nursing staffing consider unsafe.</li> <li>Carrying out a work assignment in which the nurse does not feel</li> </ul>	<ul> <li>Participants</li> <li>13.7% already changed units or hospitals due to moral distress situations.</li> <li>50.5% have considered changing work.</li> </ul>	<ul> <li>Full-time nurses obtained higher</li> <li>Moral distress scores than those working part-time (p &lt; 0.05)</li> <li>Age, years of nursing experience, and years of pediatric oncology or</li> </ul>

						professionally competent.  • Work with nurses who are not as competent as patient care requires.  • Providing care that does not relieve the child's suffering  • Physicians feared an increasing dose of pain medication will cause death.  • Working with physicians who are not as competent as patient care requires.		hematology experience were not significant (p > 0.05).
LeBaron et al. (2014).	To explore the experience of MD with oncology nurses, other providers, and its potential relationship to opioid availability.	Ethnograph ic India	VI	Semi- structured interviews and field observations	N = 37 oncology nurses	<ul> <li>Opioid management</li> <li>Opioid availability</li> <li>Lack of necessary supplies: bedpans, thermometers, and protective equipment</li> <li>Inadequate staffing</li> <li>Lack of support from nursing leadership</li> <li>Staff favoritism</li> <li>Lack of training</li> <li>Physicians lack of respect</li> <li>Fear of disciplinary</li> </ul>	<ul> <li>Nursing adopted a task-oriented behavior</li> <li>Leaving the job</li> <li>Leaving the profession</li> <li>Medication errors</li> <li>Vesicant extravasation</li> <li>Avoiding patients</li> <li>Feeling guilty</li> <li>Low quality of care</li> </ul>	not reported

						actions for not following orders • Being blamed for adverse outcomes		
Lievrou w et al. (2016)	To explore variations in coping with moral distress among physicians and nurses in a university hospital oncology setting.	Thematic analysis of qualitative interviews. Belgium	VI	Interview	N = 18 Oncology nurses	<ul> <li>Prejudice from doctors</li> <li>Moral disagreements among physicians and patients</li> <li>Inability to advocate for their patients</li> <li>Unclear communication between patients and physicians</li> </ul>	<ul> <li>Coping mechanisms based on feelings and experiences</li> <li>Frustration and powerlessness</li> <li>Emotional exhaustion and burnout</li> </ul>	not reported

Pavlish et al. (2015)	To examine the acceptability	Descriptive qualitative analysis.	VI	Ethics Screening and Early	N = 28 Oncology and ICU	Top indicators for moral distress: • Unable to alleviate	<ul><li>Providers' distress</li><li>Moral</li></ul>	not reported
	and feasibility of an ethics	US		Intervention Tool	nurses	<ul><li>patients' suffering,</li><li>Families' unrealistic</li></ul>	<ul><li>desensitization</li><li>Absenteeism</li></ul>	
	screening and					expectations.	• Burnout	
	early intervention					<ul> <li>Aggressive treatments in patients</li> </ul>	<ul> <li>Leaving the profession.</li> </ul>	
	tool for use by nurses caring					with poor prognosis • Uncertainties with		
	for critically					the plan of care		
	ill patients							

Rice et al. (2008)	To determine the prevalence and contributing factors of moral distress in medical and surgical nurses.	Prospective cross-sectional analysis. US	VI	MDS	N = 284 Clinical nurses	<ul> <li>Perceived futile treatments</li> <li>Deception</li> <li>Perceived euthanasia</li> <li>Working with physicians and nurses perceived as incompetent</li> <li>Inability to control pain and suffering</li> </ul>	<ul> <li>Oncology nurses, stem cell transplant, in particular, reported the highest score of moral distress</li> <li>Frustration</li> <li>Anger</li> <li>Powerlessness</li> <li>Reluctant to return to work</li> <li>Change jobs</li> <li>Low quality of care</li> </ul>	• Age >34 years associated with moral distress to futile care • Current employment >3 years was associated with high intensity of moral distress related to futile care • Nursing
								experience >6 years was associated with a high intensity of moral distress to
								incompetent physician and nurse practices, futile care, and deception.

Sirilla	To explore	Cross-	VI	MDS-	N = 73	Inadequate pain	Distancing from	• Education
(2014)	relationships	sectional		Revised	Oncology	management	patients and	was inversely
, ,	between nurse	survey.			nurses	<ul> <li>Futile treatment</li> </ul>	patient care areas	related to
	characteristics	US				<ul> <li>Unable to advocate</li> </ul>	• Low quality of	moral distress
	and moral					for the patients	care	scores, with
	distress.					<ul> <li>Unable to influence</li> </ul>	<ul> <li>Surgical</li> </ul>	scores being
						patient care decision	oncology nurses	lower as
						<ul> <li>Inadequate staffing</li> </ul>	reported the	education
						<ul> <li>Unable to alleviate</li> </ul>	highest moral	increased.
						pain and suffering	distress scores.	<ul> <li>Nurses older</li> </ul>
						<ul> <li>Working with</li> </ul>	• 22 of the 73	than 50 years
						perceived incompetent	participants	reported the
						nurse or physician	considered leaving	highest moral
							a previous position	distress scores
							related to moral	• No
							distress, and five	significant
							left a previous	correlations
							position.	found among
							• 10 of the 21	age or years of
							nurses who	experience and
							reported moral	moral distress.
							distress scored	•
							higher than 100	
							are currently	
							considering	
							leaving their	
							position.	

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#### CHAPTER III

#### PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

This qualitative study used a grounded theory approach to explore hematologyoncology experiences of moral distress. The study design used constant comparative
analysis to adjust the data collection questions in order to gain a greater understanding of
the processes and strategies nurses used when attempting to resolve moral distress. The
scarceness of research in which hematology-oncology nurses experienced moral distress
prompted the opportunity to explore the phenomenon using a grounded theory approach.
In this study, involving the analysis of the qualitative interviews, approval was obtained
from the cancer center and the educational institution where the principal investigator is a
doctoral student.

# **Setting and Population**

This study was conducted at The University of Texas MD Anderson Cancer

Center. The hematology-oncology units include three Leukemia units, one

Lymphoma/Myeloma unit, and two Stem Cell Transplant units. These units include 252

inpatient beds, with an average nurse to patient ratio of three patients to one nurse around
the clock. This ratio fluctuates depending on variables of patient acuity, nursing
expertise, and staff availability. Recruitment of participants for the study occurred via
email and flyers (see Appendix A) posted on these units' break and locker rooms to
encourage nurses to self-identify for the study. Once nurses communicated interest to
participate in the study, a process of selection according to inclusion and exclusion

criteria determined participation in the study. A response email was sent to eligible participants to convene the interview time and location (see Appendix B).

## **Inclusion Criteria**

A purposeful sampling method was used to recruit participants. The inclusion criteria for participation were:

- Clinical nurses working in any of the Adult inpatient
   Hematology/Oncology units at MD Anderson Cancer Center (specifically, leukemia, lymphoma, and stem cell transplant units)
- Clinical nurses classified as full-time employees
- Nurses aged 18 and older
- Individuals with a clinical nurse job title
- Individuals with greater than six months experience at MD Anderson
- Nurses who agree to provide informed consent and participate in an interview
- Nurses who speak English
- Nurses who identify as having experienced work-related moral distress

#### **Exclusion Criteria**

#### Exclusion criteria were:

- Nurses working in the leadership, advanced practice (nurse practitioner roles), or research roles
- Clinical nurses who float to the hematology units but are not primarily assigned to these units

Participants were purposeful sampled to ensure diversity in age, gender, experience, unit, or patient population until data saturation was achieved. Purposeful sampling, a frequently used sampling technique in grounded theory research, involves the strategic selection of study participants to ensure diversity across defined study variables, for example, age, gender, race, and years of experience (Marshall, 1996). Once participants signed consent for participation, demographic information determined heterogeneity. Diversity specifically focused on the inclusion of both male and female participants, participants identifying as American Indian or Alaska Native, Asian, Black or African American, Hispanic or Latino, Native Hawaiian or Pacific Islander, White, or Other as classified by the National Institute of Health (NIH) (2015). See Appendix C for a list of demographic characteristics. The age of the participants represents different generational groups, including Traditionalists born between 1925 and 1945, Baby Boomers born between 1946 and 1964, Generation X born between 1965 and 1976, and Millennials born between 1977 and 2000 (Phillips, 2016).

For validation and accuracy of demographic information, the Human Resources

Department at MD Anderson provided a report containing a hire date, job title,

employment status, and full-time equivalence. See Table 2 for participants' screening

criteria.

Table 2
Screening Criteria of Participants

Screening Item	Source Information	Response for Inclusion

MD Anderson Hire Date	Human Resources Database	Greater than six months from screening date
Job Title	Human Resources Database	Clinical Nurse
Employment (Full Time Equivalence) Status	Human Resources Database	Full Time
Experience of Moral Distress	Nurse	Yes
Gender	Nurse	Female / Male
Race	Nurse	American Indian or Alaska Native, Asian, Black or African American, Hispanic or Latino, Native Hawaiian or Pacific Islander, White, or Other
Years of Hematology Experience	Nurse	>6 months to 1 year, > 1 year to 2 years, > 2 years to 5 years, > 5 years to 10 years, and > 10 years
Age	Nurse	Traditionalists (1925- 1945), Baby Boomers (1946-1964), Generation X (1965-1976), and Millennials (1977-2000)

# Sample Size

A sample size of up to 30 hematology-oncology inpatient nurses was proposed for this study with saturation, ultimately determining the number of participants. Participant enrollment occurred until iterative analysis of each interview and the data set as a whole suggested thematic saturation of data was achieved. Saturation occurs when there is a repetition of previously gathered information, confirmation of previously gathered data,

and participants are providing no new information (Marshall, 1996). Establishing the sample size for the study required further review of the literature for similitude in research design. Three grounded theory studies reported data saturation at various points. Vishnevsky, Quinlan, Kilmer, Cann, & Danhauer (2015) reached data saturation at 30 participants while studying personal growth and wisdom among oncology nurses using a grounded theory approach. Edwards, McClement, and Read (2013) conducted a moral distress grounded theory study in a sample of nurses in long-term care, reaching saturation at 15 participants. Musto and Schreiber (2012) reached data saturation with 12 participants when exploring the processes mental health nurses use to ameliorate moral distress.

# **Protection of Human Subjects**

The University of Texas MD Anderson Cancer Center Institutional Review Board (IRB) and the Texas Woman's University at Houston Committee approved this study for the Protection of Human Subjects. Appropriate measures were delineated to protect participants' information according to the processes outlined by both institutions. The researcher de-identified data on the audio recordings and utilized no participant names or identifiers. If a participant mentioned his or her name or that of a patient or staff member on the audio recording, the transcription omitted this information. Code numbers rather than the participants' real names appeared on the transcribed documents. These codes linking the participants' demographic information and audio recording remained confidential due to the potentially sensitive nature of the interview content. The principal investigator maintained a log of study participants and reported to the institution's IRB.

All data included for analysis, together with that of individuals who stop their interview early, unless the participant requested to no longer be included in the study. Study data, including interview transcripts, digital recordings, are encrypted password protected on a secure institutional network drive. Only study staff listed on the delegation of authority log have access to the data.

#### **Data Collection**

Interviews with nurses working on inpatient hematology-oncology units at The University of Texas MD Anderson Cancer Center served as the data collection method. Once the participant signed the informed consent (see Appendix D), he or she completed a demographics-screening form. The principal investigator explained the protocol and answered any questions to eligible participants. A semi-structured interview guide (see Appendix E) was used to elicit the data for analysis. The procedure of the interview for data collection was as follows:

- Each consented participant was interviewed at least once.
- Interviews were conducted at times convenient to nurses' availability and preference on MD Anderson's main campus. Nurses selected whether they would prefer to be interviewed during or outside of a scheduled work shift. The principal investigator confirmed with individuals who wished to complete the interview during their shift that patient care coverage was appropriate to allow the nurse to participate. Traditionally, lower volumes of workload in the hematology units may occur in the afternoon, on weekends, late afternoons, and evenings and nights.

- Interviews were conducted for approximately one hour.
- The study principal investigator conducted the interviews.
- Interviews were audio-recorded to ensure all participant feedback was documented. The audio recordings were transcribed by a professional transcriptionist and by the principal investigator.
- Although suffering or distress was not anticipated during the interviews, if participants became distressed by interview content or chose to discontinue participation for this or any other reason, they could stop participation at any time. Should they need psychological evaluation, the participant would be referred either to the institution's Employee Assistance Program or to a Counseling Specialist within the Nursing Workforce Development Department for further psychological support as needed.
- Once the interview was completed, the participant remained on study until
  the last interview was completed with the last study subject documented
  by the principal investigator in a note to file.

# **Data Analysis**

Grounded theory methodology, well-articulated by Glaser and Strauss (1967), uses a stepwise iterative approach to data analysis, which begins upon completion of the first interview. This type of data analysis also referred to as a constant comparative method, uses a cyclical process of research design, collecting and analyzing data, developing a coding scheme for that data, and continuing sampling and analysis until data

saturation is achieved. Glaser and Strauss (1967) delineated four stages of comparative method as follows: 1) comparing incidents of compatible categories. For instance, the researcher codes incidents into categories as they start to emerge, creating new categories when new events present different characteristics. 2) Interacting categories and their properties, in this stage, the researcher uses memos to describe the properties of the incidents that confirm the category. The comparative analysis will evolve from relations among categories to associations between the properties and constructs within the categories. 3) Delimiting the theory, as the events fulfill the properties, a reduction in the number of new categories evolved. This reduction, in turn, uncovers fewer but higher-level concepts limiting terminology to saturation of data. 4) Writing theory, at this stage, the researcher developed detailed information based on discussions in memos and content behind the categories that will become themes of the theories.

The constant comparison uses writing memos and drawing diagrams to associate similar and different emerging themes in the form of codes and categories (Corbin, 2017). Memos are the records of the investigation to keep track of the developing categories and their relationship during analysis. Supplemental to memoing, the researcher draws diagrams to assist in formulating and visualizing all relationships between concepts and core categories (Corbin & Strauss, 2008). The defining characteristic of the grounded theory includes data collection, ordering, and analysis that continues cyclically with three types of data coding, open, axial, and selective, as described by Glaser and Strauss (1967):

- Open coding: intense line-by-line reading of interview transcripts to
  evaluate the data and develop preliminary codes that can continually be
  revised as new data emerges.
- 2. Axial coding: is an examination of the relationship within and between coding categories to develop a coding paradigm.
- Selective coding: is the development of more abstract mutually related categories into theoretically informed concepts.

Within and between each step, analysis of new data with each introduced interview set the tone for subsequent interviews. The exhaustive analysis of empirical data grounded the concept development by connecting mutually related categories. Data analysis began as soon as the first interview was completed. The principal investigator independently reviewed all transcripts as they became available using the steps described above. A manual method to organize, classify, and analyze the qualitative data aided linking emerging themes. Careful data collection and analysis ensured trustworthiness, an indicator of consistency in qualitative research (Patton, 2002). Once these experiences were organized into conceptual categories of data, a theoretical sampling strategy aided the researcher to refine and identify processes through a rigorous procedure of constant data comparison (Glaser & Strauss, 1967).

## **Scientific Rigor**

In this study, rigor was ensured by following Lincoln and Guba's (1985) model of trustworthiness. This model employed in the collection and analysis of data, which lead the emergent constructs and subsequent categories. Establishing trustworthiness for

qualitative research requires four criteria: credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985). Credibility refers to confidence in the truth of the data and interpretations of that data. Credibility involves self-awareness of the researcher. To help increase awareness, the interviewer kept a journal to record memos about content and process interactions. The journal allowed the interviewer to record and later reflect on study materials. Dependability is established when a research study can be audited. Lincoln and Guba (1985) postulated that when dealing with the consistency of data, audibility should be the criterion for rigor. To establish dependability, the interviewer kept accurate records to ensure that another researcher who, having examined the data, could authenticate study data. Confirmability refers to the congruence between two or more independent people about the data's accuracy, relevance, or meaning. To establish confirmability, the interviewer collaborated with experts from the academia to review and validate data. Transferability refers to the extent to which findings from the research study can be transferred to or have applicability in other settings or groups. The rich, indepth data provided detailed descriptions of participants and settings, allowing the reader to make decisions about transferability (Lincoln & Guba, 1985). The researcher provided enough contextual references and information to allow others to arrive at similar conclusions.

#### Summary

Data obtained from this study helped designing a model of the moral distress experience with unique attributes in hematology-oncology nurses. The insights from participants helped to understand the sources of moral incongruities for the hematology-

oncology nurses that can lead to moral distress. Additionally, the findings of the study assisted in identifying strategies used by nurses in this environment when attempting to ameliorate the effects of morally stressful situations. The methodology of grounded theory in this study was carried out through a set of data gathering and constant analytic processes that led to the discovery of constructs to formulate concepts, categories, and the possible relations between them for the development of a theory of moral distress in the hematology-oncology nursing.

#### CHAPTER IV

MORAL DISTRESS: EXPERIENCES IN HEMATOLOGY ONCOLOGY NURSING

A paper submitted to the Journal of Clinical Nursing

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#### **ABSTRACT**

**Aim.** The purpose of this study is to examine the unique processes of moral distress in hematology-oncology nurses.

**Background.** There is evidence of high turnover of nurses in the hematology-oncology setting. Various nursing specialty areas have studied moral distress. However, little is known about triggers and how nurses manage moral distress in the hematology-oncology setting.

**Method.** This is a qualitative study using the grounded theory approach to examine the moral distress experiences of hematology-oncology nurses on inpatient units. A purposeful sample and data saturation yielded 15 nurses who agreed to participate in interviews.

**Findings.** Clinical and environmental factors were the main categories of moral distress in hematology-oncology nursing. Becoming aware of conflicting values when caring for patients was the first step nurses experienced prior to implementing protective measures such as blocking emotions. Becoming detached from patient care and the clinical setting was a response in the presence of unresolved moral distress experiences.

**Conclusions.** Moral distress may play a role in hematology-oncology nurses changing their job setting and specialty. The high turnover of nurses may affect the quality indicators of nurse and patient satisfaction.

Implications for clinical practice. Recognizing triggers of distressful moral events in hematology-oncology nurses creates the opportunity for the development of interventions towards prevention, anticipation, and management of these experiences. Nurse manger involvement in the daily logistics of patient care in hematology-oncology units is important to support nurses who are dealing with devastating moral experiences.

**Keywords:** moral distress, nursing retention, oncology nursing, grounded theory, nurse detachment.

### Introduction

Moral distress arises in situations "when one knows the right thing to do, but institutional constraints make it impossible to pursue the right course of action" (Jameton, 1984, p. 6). Exposure to moral distress in hematology-oncology nursing can lead to job dissatisfaction, burnout, retention difficulties, and nurses distancing from patient care areas (Neumann et al., 2016). Nurses who frequently experience moral distress reported feeling despair, job dissatisfaction, changing roles, and leaving the profession (Bohnenkamp, 2016). Indeed, Johnstone and Hutchinson (2015) highlighted that nurses working in environments with a high level of moral distress often correlated with poorer perceived ethical climate. Additionally, the negative effects of moral distress in nurses appear to affect the patient care experience, and consequently, reflect on organizations' quality ratings (Johnstone & Hutchinson, 2015). Quality ratings are measurements associated with the organizations' ability to provide high-quality health care reported by the Centers for Medicare and Medicaid Services (2019). Exploring the contributing aspects of moral distress in hematology-oncology might aid in understanding the possible unique characteristics of the experience and the processes nurses use when attempting to ameliorate the morally troubling situations.

### **Background**

The literature describes moral distress in nurses mainly through studies in emergency, pediatrics, intensive care units, and palliative care. While the attributes of the concept may translate across various nurse specialties, there is a need to further explore the potential unique attributes of the phenomenon in the hematology-oncology setting

where the incidence of moral distress is high (Corley, 2002). Exploration of the processes and progression of moral distress in hematology-oncology nurses will serve to inform whether additional concepts and attributes exist related to the hematology-oncology nurse's experience of moral distress, distinct from those experienced by nurses in other fields. For example, moral distress in emergency nurses stems from the acuity of the cases they treat, including profound trauma from violence, accidents, and sexual assault (Zavotsky & Chan, 2016). In pediatric nursing, moral distress often emerges from the duress of treating children with terminal diseases or traumatic injury (Dos Santos et al., 2018). In critical care, moral distress can appear from the prolongation of life that seems incompatible with the underlying diagnosis (Choe et al., 2015). In palliative care, moral distress can emerge from challenges in managing the pain and suffering of the dying patient (Wolf, 2016). Hematology-oncology nurses may experience moral distress related to other attributes, including duration and intimacy of care provided, that influence the occurrence of moral distress in this professional population.

The discovery and emergent therapies in cancer medicine brings a new era in the management of hematology-oncology malignancies (American Society of Hematology, 2019). In particular, in the areas of targeted therapies, epigenetics, gene therapies, immunotherapy, and regenerative medicine, promising patients' higher remission rates than with conventional chemotherapy treatments alone (American Society of Hematology, 2019). With the continuous advances in science, the incidence of serious adverse events and variety of responses increased requiring intense real-time monitoring to properly manage life threatning side effects. (American Society of Hematology, 2019).

Nurses caring for hematology-oncology patients must maintain safe level of competency in symptom management of emergent treatment protocols, devices, and technologies to deliver highest standards of care and overcome possible moral and ethical dilemmas related to the complexities of treatment protocols (Esplen et al., 2018). The moral distress experience in oncology nursing has been studied mainly in the context of general oncology settings and the events lead to burnout, compassion fatigue, and nursing grief (Wahlberg et al., 2016).

The moral distress experienced in hematology-oncology nursing is scarce in the current literature. Grounded theory developed by Glaser and Strauss (1967) guided the research. The theory has strong roots in symbolic interactionism theory (Glaser & Strauss, 1967). Symbolic interaction influences how people think about themselves and how and why they behave as they do according to learning experiences, beliefs, values, and the environment. These experiences define the perceived truth according to their interpreted meaning of objects, people, ideas, and virtues as symbols (Glaser & Strauss, 1967). Pragmatism, combined with symbolic interactionism underpins the ability of grounded theory to aid in identifying what is essential to people, what is problematic, and the process of events or actions implemented to achieve resolution. Pragmatism brings out the ever-changing process of behavior or action patterns in response to problematic situations. People respond to their beliefs as rules for actions, and the ideas produced as their perception of truth (Corbin & Strauss, 2008).

### **Methods**

#### Aims

The purpose of this study was to explore hematology-oncology nurses' experiences of moral distress in the inpatient setting. In addition, this study examined the unique processes and strategies nurses used when attempting to resolve moral distress.

# Design

Data collection and analysis in this study were conducted using methods of grounded theory, including theoretical sampling and the constant comparative process. Grounded theory methodology allows comparative analysis of the evidence of the phenomenon where little knowledge exists and is consistent with the study's aim to construct a theory (Glaser & Strauss, 1967).

### **Population and Sample**

Purposeful sampling was used in this study. The inclusion criteria for the study consisted of: (a) clinical nurses working in adult inpatient hematology-oncology units on a full-time basis, (b) individuals with greater than six months experience, and (c) nurses who identify as having experienced work-related moral distress. Individuals who worked in the leadership and advance practice roles were excluded from participation in the study. The study was conducted in a National Cancer Institute-designated comprehensive cancer center in the US. The hematology units consisted of leukemia, lymphoma, and stem cell transplant specialties.

There were 15 (N = 15) nurses represented in the sample. The participants included 11 women and 4 men. The mean age was 36.6 years (r = 27-50 years; SD = 6.84

years). Three participants worked on leukemia units (20%), seven worked on a lymphoma unit (47%), and five worked in a stem cell transplant unit (33%). Three participants reported having over ten years of hematology-oncology experience (20%), nine participants had 5-10 years of experience (60%), and three participants had 1-4 years of experience (20%). Fourteen participants attended schools in the US (93%), while one participant was educated in the Philippines (7%). Nine of the 15 participants sampled worked in other nursing specialties before hematology-oncology. Participants shared their race information, seven identified themselves as Asians (47%), two identified as black (13%), three as Hispanic (20%), and three White non-Hispanic (20%). Summary of participants' demographics is displayed in (see Table 3).

Table 3 Demographic Data

(N	=	1;	))
V	aı	ia	ıbl

Variable	n (%)
Gender	
Female	11 (73)
Male	4 (27)
Age	
Traditionalists (1925-1945)	0 (0)
Baby Boomers (1946-1964)	0 (0)
Generation X (1965-1976)	2 (13)
Millennials (1977-2000)	13 (87)
Race	
White non-Hispanic	3 (20)
Black	2 (13)
Hispanic	3 (20)
Asian	7 (47)
Years of Nursing Experience	
1-4	2 (13)
5-10	8 (53)

Philippines	1 (7)	
US	14 (93)	
Country of Nursing Education		
Bone marrow transplant	2 (13)	
Medical-surgical	1 (7)	
Critical care	1 (7)	
Oncology	7 (46)	
None	6 (40)	
Certification		
Doctoral	1 (7)	
Bachelors	14 (93)	
completed		
Highest level of education		
over 10	3 (20)	
5-10	9 (60)	
1-4	3 (20)	
Oncology		
Years of Experience in Hematolog	y-	
over 10	5 (33)	

### **Ethical Considerations**

IRB approval was obtained both from the study site and from the educational institution at which the first author was enrolled in a doctoral program. Once IRB approval was obtained, recruitment fliers were posted on the respective units, and interested individuals were further screened for eligibility and through purposeful sampling to ensure diverse participants.

### **Data Collection**

Once participants consented to participate in the study, data collection, and analysis were done using a constant comparison of the data. The unstructured interviews conducted with hematology-oncology nurses served as the primary method of data collection. Participants were asked to describe the moral distress experience and, if so, to describe the situation using the following prompts: "Tell me about a situation when you

knew the right thing to do but felt uncertain about doing it (right or wrong)?" Finally, they were asked how they had coped with the experience and what barriers they may have confronted, "How have you tried to resolve the experience of moral distress?" "What challenges have you faced in resolving the distress?" All interviews were audio-recorded and transcribed verbatim by a professional transcriptionist and by the principal investigator.

# **Data Analysis**

The interview transcripts were analyzed individually and collectively, allowing analysis time before moving on to additional participants. Implementing constant comparison of the data, allowed for a more in-depth clarification of descriptors during subsequent interviews. The researcher maintained memos for each interview that included ideas, premonitions, and inquiries arising from open codes. Glaser and Strauss (1967) referred to this process as memoing, which accumulates as written ideas providing context for emerging categories and major themes for the formation of theories. Each interview was coded manually and reviewed for emerging themes. There were three levels of analysis: (a) open coding, (b) axial coding, and (c) selective coding. Open coding is the process of labeling textual content to establish data properties. Axial coding consists of identifying relationships among the open codes. Selective coding identifies core variables and the interrelations that describe the actual theoretical connections (Glaser & Strauss, 1967). This process continued until saturation was reached, and selective codes with the most significant relationships formed the foundation for

theoretical development. Experts from academia reviewed the findings for content validity. Validation of the interviews was held with two participants.

### **Trustworthiness and Rigor**

Rigor was ensured using Lincoln and Guba's (1985) model of trustworthiness. Establishing trustworthiness for qualitative research requires four criteria: credibility, dependability, confirmability, and transferability. To establish credibility, the researcher utilized experts to review and validate data. In addition, two participants validated the qualitative analysis comparing the data and results with their experiences, thus contributing to research confirmability. To establish dependability, the interviewer maintained accurate records to ensure that another researcher who, having examined the data, arrived at similar or very similar conclusions. Transferability was enhanced by the rich, in-depth data provided detailed descriptions of participants and settings, which may allow the application of the findings in other contexts, settings, or groups.

#### **Findings**

Of the 15 individuals interviewed, age and experience appeared to influence the intensity of moral distress experienced and how it was managed, with individuals with less than 10 years of experience describing the greatest intensity of moral distress. Contributors to moral distress were classified as clinical situations and workplace environment. The clinical category evolved from those events related to clinical patient care experiences: feeling attached (n = 4), futile treatments (n = 3), unrealistic hope (n = 9), loss of autonomy (n = 6), and clarity of outcomes (n = 10). Wilkinson (1987) described moral stressors in clinical situations associated with those events perceived as

decreasing the ability to provide care in the clinical context. The second category conveys workplace experiences. Lake (2002) defined work environment moral events as "the organizational characteristics of a work setting that facilitate or constrain professional nursing practice" (p. 178). The subcategories of the workplace environment included: inadequacy of leadership support (n = 13) and special treatment considerations (n = 9). Participants who expressed being able to resolve moral distress events and maintain a work-life balance (n = 3) were individuals with at least 15 years of hematology-oncology experience.

The concepts emerging from this study were *becoming aware* and *becoming detached*. Participants became aware of barriers to care for patients when perceived obstacles made it difficult for their practice. Becoming detached occurred after a nurse has failed to solve moral distress in various ways.

# **Becoming aware**

Identification of moral distress among participants was a positive first step in planning for strategies when attempting resolution. Campbell (1980) conceptualized self-awareness as the ability to perceive, feel, and become conscious of events and sensory patterns. Rasheed (2015) argued that self-awareness in nursing not only involves examining individuals' emotions, but it also includes exploring the work environment in the context of patient care and the interactions among healthcare professionals. Becoming aware is an essential step towards the resolution of moral distress, recognition of the internal struggles characterized by stress in the presence of conflicting organizational expectations (Corley, 2002). Participants became conflicted when developing an

awareness of the moral patterns that made difficulty or were incongruent with patient care in the hematology-oncology units.

### **Clinical Situations**

Attachment. Nurses reported feeling attached to patients and committed to the wellbeing of patients. In this study, participants indicated that patient hospitalization in the hematology units typically lasted for more than two weeks. Participants revealed they suffered with patients and families when medical expectations were not met as planned. Participants consistently reported feeling emotionally involved with patients and caregivers, giving rise to the concept of feeling attached. All participants described bonding, building relationship, spending time with patients, and feeling attached.

Our patients are frequent flyers, so we get to know them, their family members, their children, grandchildren, and we develop a bond, and so when or if they get bad news or they pass away, we are hurt like as if we are losing a family member ourselves. (P1)

**Futile treatments.** The perception of prolonged aggressive treatments sparked moral distress due to their perception that treatment was futile. Participants recalled having reached a point when they at times became certain that the patient would not survive, and the treatment was seen as causing more harm than benefit, creating a morally distressful event.

Some of the treatments are very strong on the patients, and sometimes the body reacts by shutting down essential organs. Sometimes we ended up coding patients

after starting treatments causing much pain for the nurses. So we think if what we do is sometimes beneficial for the patients. (P1)

Unrealistic hope. While some of the participants expressed sadness and grief associated with the loss of a patient, there were essential distinctions of feeling powerlessness associated with frustration and anger related to unrealistic hope.

Participants witnessed medical teams offering what the participants perceived to be unattainable hope to patients and families of returning home. This was compounded by rotational schedules in which new teams of providers offered new hopes while managing the care for these patients every 15 days.

They wanted their loved one to be at home, he passed away, and that chance never came. Different teams keep on bringing different options, and I felt powerless at that time, the patients and family, really wanted to go home to spend the last days of their life, that is their wish. (P5)

Clarity of outcomes. Moral distress was experienced by nurses who felt that extending an increasing number of treatment options to patients with advanced disease was potentially misleading to patients and, therefore, perceived as unethical. Nurses felt that the discussion of additional treatment options often overshadowed a discussion of prognosis. Hematology nurses expressed challenges in terms of dealing with different medical teams who offered different perspectives on recovery. Participants perceived comfort care measurements desperately needed at the end-of-life were not considered.

Giving treatment will probably make matters worse. I am not a physician, but with my experience I have seen, I think having more of a comfort care conversation would be more appropriate. I guess that is what, majority of the time bothers me. (P15)

Loss of autonomy. Nurses perceived patient autonomy in decision making as an inherent value. Yet there were times when, due to level of consciousness, altered mental status, or other impediments, the patient was no longer able to communicate their preferences, leading to surrogate guiding healthcare decisions. In some instances, family caregivers were asking physicians for more treatments. In other instances, nurses reported patients' wishes to withdraw treatments and to be discharged home to spend the last moments of their lives conflicted with what the family members ultimately requested.

"Many times, it is driven by the family versus the patient. Because we give these investigational drugs and many times patients' conditions worsen" (P12).

### **Workplace Environment**

**Inadequacy of leadership.** The perceived lack of leadership to support nurses led to moral distress. Participants expressed how the perceived inadequate interventions, empowerment, communication, and connection with the hematology-oncology nurses were viewed as untrustworthy.

We report staff that is not doing what they supposed to be doing when caring for patients, but we never see any follow up. Though they tell say that there is a follow-up, we do not see any changes, so I have to believe them. I do not always trust the leadership. (P16)

Participants felt that leaders were also vulnerable to morally stressful events, which led to burnout and a high turnover of leadership. "We have experienced high

turnover in the leadership team. It affects the practice because there is no clear direction" (P3).

Special treatment considerations. Participants expressed that in hematologyoncology, there are treatments that require unique considerations in terms of patient
education, continuous monitoring, and long-term adverse effects. The treatments
participants were most concerned with were stem cell transplantation, chimeric antigen
receptor (CAR) T cells, and investigational treatments. Participants reported experiencing
emotional exhaustion, guilt, burnout, and suffering when caring for patients receiving
special treatments. The conditions during the administration of these treatments were
perceived as less favorable for nurses in the presence of complications without perceived
support. The absence of educational activities, poor communication, and insufficient staff
while caring for patients experiencing stem cell rejection or inflammatory responses after
receiving CAR-T cells, prompted the moral distress experienced.

Having to deal with all these complicated cases and not having enough support.

There are needs for more education regarding treatments' side effects. Also, of course, the process itself is very harsh for patients. We ask ourselves, when is this going to stop? (P8)

### **Intent to Resolve Moral Distress**

Participants detailed the processes used when attempting to resolve the moral distress they experienced. In the absence of moral resolution, participants distanced themselves from patient care. Becoming detached emerged as a conscious response in an attempt to protect moral integrity. Examination of the influence of the clinical and

environmental factors in the nursing practice, guided participants in developing action plans to alleviate moral distress.

The theoretical model of hematology-oncology moral distress emerged from participants' experiences and the processes used when attempting to resolve moral distress (see Figure 3).

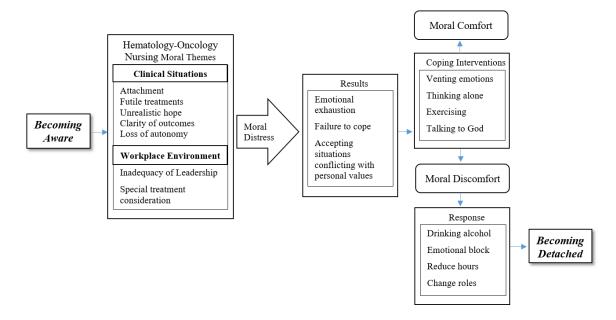


Figure 3. Hematology oncology nurses moral concepts showing becoming aware of morally distressful events in clinical situations or workplace environment. The figure represent how nurses find either moral comfort or moral discomfort and become detach from patient care areas as response to preserve moral integrity.

**Venting emotions.** Participants identified venting emotions as a way to relieve built-up tension and anxiety in the work environment. One action to manage moral distress was voicing their emotions with peers and family members. Participants

indicated these strategies to alleviate feelings of frustrations, sadness, and anger that were aroused while caring for patients in the hematology units.

Having conversations with my wife, and somewhat bouncing off ideas, and I guess just speaking out loud helps me. Not that I am waiting for her to respond and give answers or say anything, but I think when I say it out loud and speaking to her, it is like a counseling session. I think it just kind of help. (P15)

The immediate feelings of relief derived from expressing the identified moral stressors in the workplace can hardly be overstated. Participants expressed benefiting from the comfort and consolation of another person's supporting and validating shared distressing experiences.

"Talking to nurse colleagues helped more than any other people because they understand the feelings caused by different experiences in the unit" (P1).

**Thinking alone.** The trouble sense of moral incongruences in nurses with less experience concerned some of the participants, as it appeared to significantly reduce their willingness to share their experiences with others. Some expressed the need to be alone to think, in an attempt to reconcile grievances from perceived painful moral events.

**Exercising.** Other participants expressed channeling their frustrations through exercising. Walking, jogging, or running, bicycling, were some of the strategies utilized as coping strategies to alleviate moral distress.

**Talking to God.** A spiritual search for support was present; some participants stated that faith and spirituality practices successfully reduced stress and helped them to deal with distressing memories in the workplace. These coping strategies had various

levels of perceived success among the participants. The majority of individuals felt unresolved moral distress due to the pressures and demands on them perceived as more than what they can cope with.

### **Becoming detached**

In an attempt to preserve moral integrity, participants opted for alternative coping strategies to lessen the intensity of the experiences. Pavlish, Brown-Saltzman, Fine, and Jakel (2015) expressed that detachment in nursing goes beyond physical presence. In some instances, nurses consciously avoided voicing their opinions because of fear of harming relationships with medical teams, nurses, and patients. Wells (2005) identified detachment behavior in the workplace as an emotional response to stressful situations. Detachment brings distinct features that can negatively affect nursing retention and the organization. During the constant comparison of data, it became evident that participants' responses were consistent in their pursuit to preserve moral integrity. These alternative coping strategies were intended to alleviate the moral distress in the hematology-oncology units; in some cases created emotional responses that said, "thank God, it is over" (P11).

Becoming detached brought unexpected problems for nurses. Participants expressed conflicts created when distancing from patient care "I really like my job and my patients; it is not easy to distance from patient care. Although I feel relief from the suffering and moral distress events, it is kind of embarrassing failure feelings" (P11).

**Drinking alcohol.** Ramchandani et al. (2018) identified that work-related stress and alcohol use is often connected. Participants in this study shared that drinking alcohol

(n = 7) as an attempt to feelings of exhaustion, anxiety, anger, and suffering due to moral distress. However, the adverse effects of alcohol consumption, feeling tired in some cases, exceeded the coping intentions.

After a tough day at work, really stressful, just running around, and thinking about the injustices pretty much I will go home and have maybe a glass of wine, and then one glass of wine leads to sometimes a bottle (chuckles). It makes it worse because, if I am so exhausted at work, and then drinking at home, the next day, I am even more tired. So, it does work at the time as I am drinking. (P14)

Emotional blockage. Cognizant of their suffering while feeling attached to patients and families, participants' tended to dissociate themselves from patients and work-related activities in an attempt to resolve moral distress experiences. Participants tried to block their emotions using different methods, especially when suffering and unable to stop thinking about the morally distressing experiences. Consciously blocking their emotions, participants attempted to preserve their emotional integrity.

I have cried (Giggles). I have had to step out of rooms (sobs) Cannot bring it home, cannot bring it to my kids or family I think I do a pretty well a pretty good job at blocking the emotional distress that I have here on the unit, so it doesn't get exemplified in my family. (P2)

One participant, with more than 15 years of hematology-oncology experience, shared that she metaphorically adopted a technique early in her career to be able to deal with moral distress.

We go home drained, when I started here as a new nurse, one of the best advice I got was you come in, you leave yourself at the door and on your way out, you pick it up and go home to your family. Sometimes, it is not that easy, but I think it is a growing process, I think it has made me a stronger nurse. (P15)

**Reducing work hours.** In an attempt to separate from the intensities and frequencies of moral distress in the hematology units, participants reduced work hours.

"Some people cannot handle it anymore, that is why some of them are going parttime because they are just frustrated, and every time they address the issues, there is no resolution" (P1).

**Changing roles.** Participants intensified strategies in order to change positions and advance their careers by occupying different roles to lessen the exposure to distressful moral events.

#### Discussion

This study revealed that two main concepts, becoming aware was associated with the identification of the moral distress experienced, and becoming detached related to actions of self-preservation of moral integrity. The concept of becoming aware evolved in nursing from Maslow's view of self-awareness as a basic humanistic approach using the term self-actualization (Hotchkiss & Lesher, 2018). Rasheed, Younas, and Sundus's (2019) definition of awareness related to a dynamic transformation of self-insights and presence guiding behavioral conduct for a healing environment. The attributes of the concept include introspection and self-consciousness of beliefs, values, and feedback (Rasheed et al., 2019). In the current study, nurses reported identifying their convictions

and values and perused finding solutions using available resources when perceived clinical or workplace environment factors interfered with nursing practice.

Participants emphasized the perceived inadequate leadership support during stressful situations to assist in dealing with the complexities of patient care exacerbated the moral distress experienced. Kodama and Fukahori (2017) reported positive leadership attributes when implementing interventions encompassing organizational and individuals perspectives. Managing administrative indicators while respecting personal beliefs, being proactive, and having empathy for staff nurses played a significant part in nurse retention and patient satisfaction. Kvist et al. (2019) identified nurse leaders' presence and actively providing feedback and rewards to nurses was pivotal for successful relations with clinical nurses. Siirala et al. (2019) described nurse leaders' effectiveness and meaningful collaboration and communication while managing the daily unit operation. In contrast, nurses in this study identified ineffective management when there were no perceived interventions in the presence of incompetent staff. The perceived absence of nurse managers to support the daily operation while caring for hematology-oncology patients exacerbated the moral distress experienced.

Participants attempted to resolve moral distress using well-planned coping strategies. When these strategies failed to reach moral comfort, participants opted for alternative escape-avoidance strategies. The most notable expressed alternative strategies included drinking alcohol, blocking their emotions, and distancing from the patient care areas by either reducing work hours, changing roles, or changing positions. Wells (2005) identified mindful detachment as purposely drawing away from stressful thoughts that

may represent a threat to the individual's wellbeing. In this study, participants reported strategic actions in order to attempt to restore and preserve their emotional integrity. When these actions were unsuccessful in achieving moral comfort, participants opted for more complex coping strategies, involving cognitive escape and distancing from patient care.

Another aspect of nurses distancing from patient care areas brought unintended consequences for participants. Wilkinson (1987) identified that individuals could experience splitting off or psychological doubling in situations in which oneself a sense of the good may conflict to preserve moral integrity. In this study, nurses who planned to distance from patient care areas explained anticipating hopefulness, yet feeling sad in detaching from direct patient relations. Friganovic et al. (2019) found that escape avoidance in nursing was related to emotional exhaustion, depersonalization, and lack of professional accomplishment. Becoming detached as a coping strategy created new challenges for nurses, as they reported struggles to balance moral distress experiences and the overwhelmed emotions related to distancing from patient care.

Becoming detached refers to the ability to neutralize the emotional demands of patient care with a balanced attitude between objectivity and emotional involvement (Cadge & Hammonds, 2012). These attitudes can have either a positive or a negative valence, which may reflect multiple underlying values. The antecedents of the concept of becoming detached include emotional exhaustion, failure to cope, and accepting unfavorable situations, that frequently came into conflict with personal values (Cadge & Hammonds, 2012). The variability of these experiences manifested in this study ranged

from self-imposed isolation, frustration, anger, to burnout. The experiences in this study parallel a Glaser and Strauss (1965) study, in which while nurses experienced an impulse to comfort patients, they engaged in strategies of both "outright avoidance" and "expressive avoidance" to avoid emotional attachment in situations they perceived incongruent with their practice.

#### Limitations

There are some inherent limitations to this study. Data was gathered in one cancer center with a small sample. Additional obstacles to the study involved the unwillingness of potential participants to be interviewed due to perceived high workload, lack of time, insufficient coverage to care for patients, and not feeling supported by the hospital.

Lastly, the participants were not followed over time. Therefore, interpretations of stressful moral events and the long-term repercussions should be interpreted with discretion.

### **Conclusion**

This study demonstrates consistency with grounded theory methodology. The concepts that emerged from this study, *becoming aware* and *becoming detached*, described the clinical and environmental processes and phenomena of moral distress in hematology-oncology nursing. To further disentangle the effect of moral distress, this study analyzed the sensitivity in which hematology-oncology nurses raised awareness and formulated interventions in an attempt to resolve the distressful situations. Awareness of morally disturbing events was associated with active coping and planning to address stressors and to maintain moral integrity. Years of experience may influence how nurses

dealt differently with moral distress. Participants with less experience in hematologyoncology tended to reduce their willingness to vent their emotions with others. There was
no significant difference in moral distress when comparing age, gender, and educational
levels. Unable to reach moral comfort, some nurses opted for distancing from patient care
areas. Leadership presence and their supporting role in clinical practice emerged as a
highly influential in the prevention of moral distress, and perhaps having the potential to
affect nursing retention.

The study findings suggested that there are situations in which nurses found moral challenges. The narratives of most concern were situations related to caring for patients for prolonged periods. The moral distress experience was exacerbated when confronting ethical and moral dilemmas related to various aspects of patients' illnesses. Other identified reasons focused on issues concerned with perceived communication deficiencies by healthcare professionals and the complexities associated with special treatments. Special treatment considerations played a significant factor in nurses' moral distress due to the uncertainties associated with available educational and leadership support for nurses.

### **Relevance to Clinical Practice**

Moral distress has implications for the nurses and patients in the hematologyoncology setting. Morally distressing situations contribute to nurses distancing
themselves from direct patient care, which can negatively affect nursing retention. Based
on the findings of this study, nurses develop an awareness of morally stressful situations
from either clinical practice or from the workplace environment. The associated

processes, when attempting to resolve moral distress, can manifest in moral comfort or additional moral discomfort and suffering. In the presence of unsuccessfully resolving the stressful experiences, nurses distance from direct patient care as a coping mechanism.

The effects of moral distress in hematology-oncology nursing include reducing work hours, changing roles, and leaving the profession.

Organizations have the opportunity to plan for potential moral stressors affecting hematology-oncology nurses. Leadership presence in inpatient care areas can validate knowledge for planning and decision making to minimize the effects of moral distress. Also, identification of education opportunities for nurses concerning complex cases, ethics committees, and in particular at the end-of-life, may aid in anticipating and managing moral distress situations. Future research directions may benefit from investigating the effects and the costs associated with high nursing turnover, including managers who appeared to be vulnerable to moral distress events in the hematology-oncology units.

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#### CHAPTER V

### SUMMARY OF THE STUDY

The purpose of this study was to gain a better understanding of the unique processes of moral distress in hematology-oncology nurses. This chapter provides a summary of the nurses' experiences, as well as interventions used when attempting to resolve moral distress. Studying the lived experiences of hematology nurses was vital because it offered unique perspectives of their clinical experiences. Furthermore, findings can validate the implication for nursing practice and complement future research under similar contexts.

#### Introduction

This grounded theory study explored the experiences of moral distress in hematology-oncology nursing using a grounded theory approach. Individual interviews were conducted using a semi-structured interview guide to identify the processes and factors that morally impact nurses in this specialty. A voluntary purposeful sample of 15 full-time clinical nurses participated in the study. Interviewing was the means of data collection following the grounded theory methodology. As data analysis progressed using recordings and transcriptions, newly obtained data were compared, ensuring constant comparison until reached saturation of themes and categories. Demographic information collected served to determine eligibility and compared with the data to determine individuals who were likely to experience distressful moral events. Academic and clinical research experts analyzed the data for validity purposes. The data presented as raw and

aggregate forms confirmed techniques were consistent with the grounded theory approach.

# **Discussion of Findings**

The findings from this study provided sufficient descriptors of the processes nurses encountered while experiencing moral distress in the hematology-oncology units. The sources of the experience are, in many cases, similar to nurses working in other specialty settings. The literature search provided clear information from the perspective of general nursing oncology practice. The non-existence research studies in the hematology-oncology setting suggested that the research on this topic was needed. This study began to fill the gaps of missing information from the hematology-oncology nurse perspective.

Using Glaser and Strauss's (1967) methodology, the overarching categories identified relate to clinical or workplace environment situations. The clinical situations category pertained to feeling attached, futile treatments, unrealistic hope, clarity of outcome, and loss of autonomy. The workplace environment category included inadequacy of leadership and special treatment considerations, which interrelated with clinical situations. The repetitive exposure to these events was perceived as barriers to the nursing practice in the hematology-oncology specialty, and, therefore, threatened the safeguard nurses' emotional integrity. Jameton (1984) conceptualized this experience as moral distress in response to nurses concerned about encountering obstacles when providing compassionate care to patients. Corley (2002) extended the concept creating the theoretical model of moral distress, describing the processes and the impact on nurses

when attempting to resolve these experiences, either attaining resolution and moral comfort or moral suffering leading to burnout.

### **Becoming Aware**

Becoming aware emerged as participants acquired greater mindfulness of the difficulties presented while caring for hematology patients. When these difficulties were incongruent with personal and professional values, the experiences were reported as moral distress. Becoming aware of the problems required, as expressed by participants, being able to challenge owns beliefs and call for the courage to act, the interventions led to either moral resolution or in most of the cases, moral suffering, and burnout. Rodgers (2000) formulated that individuals must maintain self-identity and recollection of life events for self-awareness to occur. The predominant antecedent of the lived experienced in this study was that participants remained cognizant of their identity as hematology-oncology nurses, feeling attached to patients, and the recognition of disagreement between their beliefs and perceived deficiencies in communication, and the uncertainties associated with special treatments. Participants reported awareness of the incongruences and difficulties of caring for patients under these conditions.

Participants identified feeling attached to patients and caregivers because of prolonged hospitalizations. The closed encounters influenced building relationship and trust in the most vulnerable moments of patients' lives. In some instances, nurses suffered alone with patients and felt morally disturbed when medical teams offered perceived futile treatments, in the presence of unclear communications. The predominant theme exacerbated moral distress emerged from a perceived unrealistic hope, clarity of

outcomes, and loss of autonomy. For instance, in the presence of either caregiver making decisions that differed from patients' wishes, medical teams offering perceived unrealistic hopes, or unable to grant patients' desire to withdraw treatments. The aggravating factors of moral distress intensified in the presence of perceived futile treatments, or when do-not-resuscitate orders, comfort care measurements, and discharge planning discussions did not occur frequently enough or occurred too late for some patients.

Intending to alleviate the internal moral tensions, participants initially voiced their concerns venting their emotions, spent time thinking alone, exercised, and talked to God. In the presence of frequent recurrences of morally distressful events, participants used different and combined techniques in the quest for moral comfort. Moral distress was not always resolved, creating extreme and notorious decisions to distancing themselves from patient care as way of preserving moral integrity. The escape-avoidance techniques used included drinking alcohol, blocking their emotions, reducing their work hours, and change nursing roles.

# **Becoming Detached**

In this study, a relation was uncovered between the intent to resolve moral distress and becoming detached from patient care with the intent to restore moral integrity. Wells (2005) maintained that mindful detachment includes planning with clear goals to escape ethical and moral work-related situations. In the absence of inner-awareness processing with clear goals, detached mindfulness is an emotional response without critical evaluation of the consequences. In this study, participants reported strategic actions with

the intention to preserve moral integrity. Nurses described awareness of the surrounded events, planning, and responding in ways to alleviate suffering in the presence of either clinical or workplace environment moral events. The strategies used are exemplified, such as deciding to distance themselves from patient care activities. Participants utilized strategies that were not independently developed but intertwined with each other. For instance, some participants planned to reduce their work hours, while advanced their education to occupy different roles, switched to different roles or even professions.

Becoming detached was a coping strategy used by hematology-oncology nurses to avoid and prevent moral threats in their profession. The unintended consequences for nurses who remained in the units were evident by the struggles that included feeling exhausted, burnout, and obligated to accept situations conflicting with personal values. Participants revealed that revolving moral distressful events created demoralizing situations for those who remained in the units. Distancing from patient care was reported because of emotional exhaustion, hopelessness, and burnout. Becoming detached as a coping strategy created new challenges for nurses, as they reported struggles to balance moral distress experiences and the overwhelmed emotions related to distancing from patient care.

### **Recommendation for Future Studies**

This research study developed nursing knowledge by unveiling themes associated with moral distress in hematology-oncology nursing. It explored the contributing factors of moral distress and the processes nurses used when attempting to alleviate the experience. Future research should look at the effectiveness of potential interventions

designed to ameliorate moral distress in hematology-oncology nursing. Other possible favorable research could focus on the unique constructs of moral distress affecting leaders in this specialty area. Knowing more about moral distress affecting charge nurses and nurse managers will aid elucidating the high turnover of nurses in these roles. Also, future research must focus on practical education activities to prepare nurses in decision making when confronting moral distress events.

# **Implications for Practice**

The findings in this study can be useful for various roles of nurses practicing hematology-oncology, leadership in particular who possess great potential to impact the nursing practice. Leadership involvement in patient care coordination, nurse assignment, and recognition of possible education needs can provide support to clinical nurses in this setting. Future research may use current findings to explore the possible impact of interventions designed to build knowledge and confidence in managing moral distress in this setting. These recommendations may help inspired individuals to reorganize their career path as hematology-oncology nurses and to optimize their ability to achieve their fullest professional potential.

### **Conclusion**

Research on moral distress in hematology-oncology nursing is scarce. This study provided information about the unique processes nurses go through when confronted with disturbing moral experiences. Understanding the factors preceding the events and the decisions nurses make when attempting to solve the experience, may support clinical nurses preserving emotional integrity. Moreover, this study identified the negative impact

that moral distress may exert on patient care and nursing retention. The grounded theory approach used helped uncovered the nursing experiences of moral distress in hematology-oncology. In addition, the process nurses used when attempting to reach moral resolution and the coping strategies when facing moral discomfort. The concepts that emerged from this study, becoming aware and becoming detached alone with themes and processes when attempting to cope with the experience aided in developing the model of moral distress in hematology-oncology nursing.

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 $https:/\!/doi.org/10.1097/TME.0000000000000100$ 

APPENDIX A

Recruitment Flyer



### **Volunteers Needed for Research Study**

Clinical Nurses are sought for a qualitative research study evaluating the experience of moral distress among nurses in the hematology-oncology setting. Moral distress is defined as "a phenomenon in which a nurse knows the morally right course of action to take, but institutional structure and workers create obstacles to accomplish these actions"

Eligible participants include clinical nurses in a full-time position who have worked at MD Anderson for at least six months and have experienced moral distress. Participation is at the discretion of the primary investigator.

If selected to participate, you would complete an interview lasting approximately 1 hour. The interview will be audio-recorded. However, all identifying information (e.g. your name) will be removed when the interview is transcribed (transferred from audio to paper).

This study is approved by The University of Texas MD Anderson Cancer Center and the Texas Woman's University Institutional Review Boards.

If you are interested in participating, please contact Joaquin Buitrago at jabuitra@mdanderson.org

1. Jameton, A. (1984). *Nursing practice: the ethical issues*. Englewood Cliffs, NJ: Prentice-Hall.

APPENDIX B

E-mail Response

Hello, Participant's name

This is Joaquin Buitrago, the researcher at MD Anderson Cancer Center and doctoral

student at Texas Woman's University. I am conducting a study on moral distress in

Hematology-Oncology nurses. You have expressed interest in participating in the study

and based on the questionnaire and demographic information; you qualify to participate in

the interview.

As specified on the flyer, the interview will last approximately one hour and will be audio-

recorded. However, all identified information (e.g. your name) will be removed when the

interview is transcribed.

Please let me know when a convenient time and location is best for you to set up the

interview.

With all your respect,

Joaquin Buitrago

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APPENDIX C

**Demographic Questions** 

Question	Response	
Gender	Male / Female	
Race	White / Black / Asian / Pacific / Islander /	
	Other	
Age	In years	
Years of Nursing Experience	In years	
Years of Experience at MD Anderson	In years	
Years of experience in Hematology-	In years	
Oncology		
Highest level of education completed	Associated Degree, Bachelor's Degree,	
	Master's Degree, Doctoral Degree, Other	
Certification	Yes / No	
If yes,		
Type of certification:		
Country in which Nursing Education was	Name of the Country	
completed		
	I .	

APPENDIX D

**Informed Consent** 

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# MDAriderson Cancer Center

#### Specialized Informed Consent

# INFORMED CONSENT/AUTHORIZATION FOR PARTICIPATION IN RESEARCH

Exploring Hematology/Oncology Nurses Experiences of Moral Distress Using a Grounded Theory Approach 2017-0409

#### Subtitle:

Study Chair: Joaquin A. Buitrago

The goal of this research study is to learn about hematology nurses' experiences of moral distress. In this study, moral distress refers to a time when you know the right thing to do but institutional constraints make it nearly impossible to pursue the right course of action.

If you agree to take part in this study, you will have a one-on-one interview with the study staff about your experience as a nurse at MD Anderson. You will be asked questions about your experience of moral distress, what has caused distress for you as a nurse, and how you have tried to resolve moral distress.

The interview will be recorded using audio digital recordings and should take about 1 hour. The interview will also be transcribed (typed up so a paper or digital copy of the interview is available).

Information, such as your age, race, and years of experience will also be collected from you at the start of the interview.

Information learned as part of your participation in this study will not be used against you during your performance evaluation nor will it be reported to your supervisor. However, you may be encouraged to call the Institutional Compliance Office's anonymous hotline or report any patient safety issues in the Safety Intelligence system.

Your information, audio recordings, and typed audio recordings (collectively known as your "study data") will be stored in an encrypted password protected electronic file on a secure institutional network/drive at MD Anderson that will only be

Protocol 2017-0409 March 7, 2018 Page 2 of 3

accessed by the study chair and the study staff. To protect your confidentiality, the researchers will use a code, instead of your name, when the interview is typed. However, your voice may identify you. Your study data will be used for study puijposes only and may be used for future Institutional Review Board (IRB)-approved studies. The IRB is a committee of doctors, researchers, and community members. The IRB is responsible for protecting study participants and making sure all research is safe and ethical.

You may be asked to participate in a follow-up interview if additional information is needed. Your study participation will be over when the last interview is conducted with the last person.

You should discuss the risks of **interviews** with the study chair. The known risks are listed in this form, but they will vary from person to person. Some questions may make you feel upset or uncomfortable. You may refuse to answer any question. If you have concerns after completing the interview, you are encouraged to contact your doctor or the study chair.

If you become distressed when participating in interviews and you feel unable to complete the interview, the interview will be stopped. You may be referred to the Employee Assistance Program or to a Counseling Specialist within the Nursing Workforce Development Department for follow-up.

**Interviews** may contain questions that are sensitive in nature. You may refuse to answer any question that makes you feel uncomfortable. If you have concerns about completing the interview, you are encouraged to contact your doctor or the study chair.

If you suffer injury as a direct result of taking part in this study, MD Anderson health providers will provide medical care. However, this medical care will be billed to your insurance provider or you in the ordinary manner. You will not be reimbursed for expenses or compensated financially by MD Anderson or Texas Woman's University for this injury. You may also contact the Chair of MD Anderson's IRB at 713-792-2933 with questions about study-related injuries. By signing this consent form, you are not giving up any of your legal rights.

If you become injured or ill as a direct result of taking part in this study, the sponsor may pay for the treatment of the injury or illness. MD Anderson cannot determine at this time what you may be reimbursed for. A financial counselor will be made available to you after the injury or illness is reported.

Unless otherwise stated in this consent form, all of the costs linked with this study, which are not covered by other payers (health maintenance organization [HMO], health insurance company, etc.), will be your responsibility.

There are no plans to compensate you for any patents or discoveries that may result

Protocol 2017-0409 March 7, 2018 Page 3 of 3

from your participation in this research.

You will receive no compensation for taking part in this study.

### Authorization for Use and Disclosure of Protected Health Information

- A. During the course of this study, the research team at MD Anderson will be collecting information about you that they may share with the parties named in Section D below.
- B. Signing this authorization form is optional. However, if you refuse to provide authorization to use and disclose your protected health information for this study, you will not be able to participate in this research study.
- C. MD Anderson will take appropriate steps to keep your protected health information private when possible, and it will be protected according to state and federal law. However, there is no guarantee that your information will remain confidential, and it may be re-disclosed at some point. Federal agencies (such as the Office for Human Research Protections [OHRP a regulatory agency that oversees research in humans]), the study sponsor, and the IRB of MD Anderson might view or receive your record in order to collect data and/or meet legal, ethical, research, and safety-related obligations. In some situations, health authorities could be required to reveal the names of participants.
- D. Your study information may be shared with the following parties:
- The OHRP
- The IRB of MD Anderson
- Texas Woman's University
- Officials of MD Anderson
- · Study monitors who verify the accuracy of the information
- Individuals who put all the study information together in report form
- E. There is no expiration date for the use of your information as stated in this authorization. You may withdraw your authorization to share your protected health information at any time in writing. Instructions on how to do this can be found in the MD Anderson Notice of Privacy Practices (NPP). You may contact the IRB Staff at 713-792-2933 with questions about how to find the NPP. If you withdraw your authorization, you will be removed from the study and the study chair and staff will no longer use or disclose your protected health information in connection with this study, unless the study chair or staff needs to use or disclose some of your research-related protected health information to preserve the scientific value of the study. Data collected about you up to the time you withdrew will be used and included in the data analysis. The parties listed in Section D above may use and disclose any study data that were collected before you canceled your authorization.

Protocol 2017-0409 March 7, 2018 Page 4 of 3

Participant Signature:_		
I		
Date:		

## APPENDIX E

Semi-Structured Interview Guide

Thank you again for agreeing to this interview. As a reminder, you are being asked to participate in this interview because you are a full-time clinical nurse on a hematology-oncology unit who has expressed experiencing moral distress. The purpose of this interview is to explore your experience of moral distress, including contributing factors, as well as any resources and approaches you have used to resolve moral distress. The interview will be audio-recorded and will last approximately 1 hour. You may stop the interview at any time and refuse to answer any question with which you are uncomfortable. While not anticipated, if you experience distress during the course of the interview you will be referred to an MD Anderson counselor for follow-up. A professional transcriptionist will transcribe the audio recording. If you identify yourself or anyone else by name these will be removed by the transcriptionist. You may be asked to participate in a follow-up interview if additional information is needed. So, let's begin...

- Tell me about your experience as a clinical nurse in the hematologyoncology unit.
- 2. Tell me about a situation when you knew the right thing to do but felt uncertain about doing it (right or wrong)
  - 1.1. What happened in this situation?
  - 1.2. What particular aspects of this situation caused you distress?
  - 1.3. How did others respond to the situation?
- 2. How has this experience affected:
  - 2.1. Your professional satisfaction?

- 2.2. Your relationship with colleagues? With family? With friends?
- 2.3. Your relationship with yourself?
- 3. How have you tried to resolve the experience of moral distress?
  - 3.1. Do you feel you have resolved the feeling of moral distress?
  - 3.2. What has been particularly helpful in resolving this experience of distress?
- 4. What challenges have you faced in resolving the distress?
  - 4.1. What best helped you to work towards a resolution?
  - 4.2. What blocked a resolution to the problem?
- 5. Did you experienced any other morally distressing situations at work?

Thank you for taking the time to provide this valuable information. Your experiences matters and will be used to better understand the hematology-oncology nursing practice.

### **Probes**

- That is interesting, tell me more...
- Give me an example.

## APPENDIX F

MDACC Institutional Review Board Approval

### Buitrago, Joaquin A

From: Latoya R. Eatmon < lreatmon@mdanderson.org>

Sent: Wednesday, October 11, 2017 4:31 PM

To: Buitrago, Joaquin A; Harty, Carolyn M; Brassil, Kelly J; Shelton, Valerie; Hollinger, Carol A;

**OPR Protocol Activations** 

Subject: Contingencies Met - Protocol 2017-0409

MDAnderson
Cancer Center
Office of Protocol Research

Institutional Review Board (IRB)

Unit 1637

Phone 713-792-2933 Fax 713-794-4589

To: Joaquin A. Buitrago 10/11/2017

From: Latoya R. Eatmon

CC: Carolyn M. Harty, Kelly J. Faltus, Valerie Shelton, Carol Hollinger, OPR Protocol Activations

MDACC Protocol ID #: 2017-0409

Protocol Title: Exploring Hematology/Oncology Nurses Experiences of Moral Distress Using a Grounded Theory Approach

Version: 04

Subject: Contingencies Met - Protocol 2017-0409

Official IRB Approval Date: 07/20/2017

On 10/10/2017 the Institutional Review Board 4 committee, chair, or designee granted approval to the above named and numbered protocol since the contingencies outlined by the IRB 4 on 07/20/2017 have been met.

It was noted that the protocol, informed consent documents (ICDs) and/or the Waivers of ICD and Authorization are satisfactory and in compliance with federal and institutional guidelines. No participants may be entered on this protocol until it has been officially activated by OPR.

In keeping with the requirements outlined in 45CFR46.109(e) and 21 CFR56.109(f), the IRB shall conduct continuing review of all protocols at intervals appropriate to the degree of risk, but not less than once per year.

You are responsible for promptly reporting to the IRB:

- any severe adverse events;
- any death while patient is on study;
- any unanticipated problems involving risks to subjects or others;
- any proposed changes in the research activity (changes may not be initiated without IRB review and approval, except where necessary to eliminate apparent immediate hazards to the subjects).

#### Please note:

- The IRB made the determination that the request for DSMB waiver may be granted.
- The IRB has made the determination that this study is not low risk for the continuing review process and must be reviewed by a convened IRB for the continuing review process.

The IRB approval expiration date is 7/20/2018.

To activate this study, please compose and send a "Request for Activation" memo in PDOL.

The existing Informed Consent and/or Waivers of Informed Consent and Authorization cannot be used until the protocol is Activated.

If a Material Transfer Agreement (MTA) is required, it must be obtained prior to Activation.

In the event of any questions or concerns, please contact the sender of this message at (713) 792-2933.

Latoya R. Eatmon 10/11/2017 04:31:24 PM

This is a representation of an electronic record that was signed and dated electronically and this page is the manifestation of the electronic signature and date:

Latoya R. Eatmon 10/11/2017 04:29:12 PM IRB 4 Chair Designee FWA #: 00000363

OHRP IRB Registration Number: IRB 4 IRB00005015

## APPENDIX G

TWU Institutional Review Board Approval



Institutional Review Board Office of Research 6700 Fannin, Houston, TX 77030 713-794-2480 irb-houston@twu.edu http://www.twu.edu/irb.html

DATE: February 6, 2018

TO: Mr. Joaquin Buitrago

Nursing - Houston

FROM: Ms. Tracy Lindsay, Director of Operations

Office of Research & Sponsored Programs

Re: Institutional Authorization Agreement (IAA) Processed for Exploring Hematology/Oncology Nurses Experiences of Moral Distress using a Grounded Theory Approach (Protocol #: 19972)

An IAA for the above referenced study between Texas Woman's University and University of Texas MD Anderson Cancer center has been processed as an expedited study. The University of Texas MD Anderson Cancer center IRB is the designated IRB providing the review for this study. According to our records, this protocol was most recently approved by the University of Texas MD Anderson Cancer center IRB on 7/20/2017.

A current protocol file with all correspondence between the researcher and the University of Texas MD Anderson Cancer center IRB must be maintained at TWU. Therefore, you are required to place on file any documentation regarding this study including modifications, extensions, notifications of adverse events, etc.

If you have any questions, please contact the TWU IRB.

cc. Dr. Ainslie Nibert, Nursing - Houston Dr. Wyona M. Freysteinson, Nursing - Houston Graduate School APPENDIX H

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