DIGNITY IN RELATIONAL DEATH CARE:

CONFRONTING NURSE MORAL DISTRESS THROUGH APOPHATIC INQUIRY

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ABSTRACT

DIGNITY IN RELATIONAL DEATH CARE: CONFRONTING NURSE MORAL DISTRESS THROUGH APOPHATIC INQUIRY

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This dissertation examines what it means to care ethically for the dying when language, policy, and even principled practice fall short. Rooted in my lived experience as a hospice nurse, I use autoethnography and apophatic inquiry to explore the need for relational dimensions of care for the dying and how moments of moral tension may culminate in nurse moral distress when not acknowledged and processed with care.

It examines an embodied ethical orientation grounded in attentiveness, dignity, and wonder. Moral distress is reframed from a professional, psychological-moral weakness to moral possibility through attunement and shared vulnerability. The experience of moral distress can indicate that something a person or community normatively values - their integrity, relationships, or commitments - is under pressure, though the significance of that signal requires further interpretation and justification.

I seek to emphasize dying as a relational event that illuminates what it means to be human, while at the same time remains a mystery to many. This dissertation treats encounters with the dying mainly as moments to engage with the mystery of human experience.

In apophatic inquiry, mystery refers to aspects of lived experience that cannot be fully captured through language but may be approached through receptivity, silence, and

wonder (Visse et al. 7-8). Human consciousness may make the event of death a reflection of the life once lived (Kokosalakis 404). Death care, even in silence, becomes an act of nurturing dignity, while presence and wonder can become forms of knowing and healing.

Part I, *Grounding*, establishes the importance of this work through its methodological framing and the compelling story of my hospice patient, Althea (a pseudonym), whose palliative sedation raised profound questions about informed consent, causing me to experience moral distress.

Part II, *Knowing*, engages the literature through Martin Buber's I–Thou philosophy of dialogue and feminist care ethics theory to demonstrate that dignity and autonomy emerge not from independence but from mutual recognition; the dialogical encounter in which nurse and dying patient meet as whole beings. Here, I challenge the dominance of individualistic autonomy in biomedical ethics, which too often abstracts reason from relationship.

Part III, *Unknowing*, returns to Althea's case as I unfold my experience of moral distress through the triad of apophatic spaces: the inner, the aesthetic, and the wondrous. Through and between these spaces I reflect on silence, vulnerability, and wonder as ethical ways of knowing, or unknowing, without "imposing ourselves" on what confronts us (Visse et al. 5). The aesthetic space includes my original artwork, which serves as a form of reflective engagement with my experience of moral distress. These images do not seek to illustrate the narrative but to remain present with what resists articulation. In this way, the unspeakable becomes a teacher, and the moral wound is allowed to reopen into deeper compassion and understanding.

Part IV, *Unfolding*, draws on Curt Cloninger's understanding of apophatic visual practices in *Some Ways of Making Nothing: Apophatic Apparatuses in Contemporary Art* (2021). While the artwork itself appears in Part III as part of the apophatic inquiry, this fourth section reflects on how that process allowed the experience of moral distress to be engaged rather than rushing to resolve it too quickly. Through this process, my inquiry gradually shifts from description toward unfolding, allowing meaning to emerge.

For my “dear ol’ Dad.”

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I remain deeply grateful to the many patients who entrusted me with their care over the years. Their courage and vulnerability continue to shape my understanding of dignity, compassion, and what it means to care for others at the end of life.

And finally, without Jim, my husband and the love of my life, this work would not have been possible. He has supported me by allowing me the space to grow into the best version of myself. His insight into human nature, along with his humor, continually brings clarity and perspective. I would be lost without him.

PART I: GROUNDING

INTRODUCTION

“All real living is meeting.” – Martin Buber

The Moment That Calls

In 2012, I witnessed the loss of autonomy, and with it, the loss of dignity of one of my hospice patients when her physician chose to treat her pain and “let her fade away” with a continuous morphine intravenous infusion without proof of consent. I have carried the weight of that moment ever since, haunted by my inability to act on her behalf. This experience became the catalyst for this dissertation. It has shaped not only my professional identity as a hospice nurse, but also strengthened my moral and philosophical commitments.

Purpose of this Dissertation

When autonomy falters, bodies fail, and language runs out, how does relational death care hold dignity in place instead of allowing it to “fade away?” And how does witnessing loss of dignity shape the moral distress of those who care for the dying?

This dissertation is grounded in qualitative and phenomenological inquiry and draws on autoethnography. It seeks to amplify the necessity of relational care at the end of life as key to safeguarding patient dignity. At the same time, it examines how barriers to this ethical model of care contribute to hospice nurse moral distress.

Hospice nurses live with an acute awareness of the tensions created by medicalized death care, where institutional practices can result in the diminishment of dignity. Nurses often struggle to make sense of these experiences, shaped as they are by professional training rooted primarily in the principle-based framework of traditional biomedical ethics.

Through apophatic inquiry, this dissertation also demonstrates how reflective and aesthetic engagement can help other clinicians make sense of experiences of moral distress that cannot easily be understood.

Significance and Context

Scholars and clinicians recognize two types of dignity, absolute dignity and relative dignity. Absolute dignity is rooted in the idea that each person has value by simply being human, while relative dignity is how individuals perceive their own sense of worth, autonomy, and meaning (Mema et al. 19). Maintaining both ideals of dignity in health care is crucial, yet patients often experience violations of their dignity, leading to negative health outcomes. For the dying, dignity is often expressed as the desire to be honored as a person, maintaining a reasonable degree of independence, control, and wholeness. They may hope to continue making decisions about their own care, to remain in familiar settings, or to preserve roles and relationships that define their identity (Angel and Vatne 1431).

Alongside this longing for autonomy, the dying also seek recognition, comfort, and the assurance that they will not be treated as objects when medical interventions shift from curative to futile. It is the experience of being reduced to an object, in Buberian terms treated as an It rather than as a whole person or Thou, that represents one of the most devastating violations of dignity in clinical practice (Woo et al. 367–68).

In the 1970s Beauchamp and Childress shaped traditional biomedical ethics in the United States, establishing the principles of autonomy, beneficence, nonmaleficence, and justice. While these principles provide important safeguards, autonomy, in this framework, is considered self-rule or the ability of a rational, independent agent to make decisions free from external influence (Beauchamp and Childress 111).

While there are emerging efforts to broaden principlist frameworks to better account for relationality, ethical reasoning within these approaches often remains organized around the application or balancing of these biomedical principles. Relationships are increasingly recognized as morally relevant, with the patient still commonly positioned as a primarily autonomous decision-maker. Relational ties function as contextual influences rather than as foundational to patient agency. This can limit the framework's ability to fully attend to the relational and interdependent dimensions of end-of-life ethical experiences.

Feminist care ethics challenges this paradigm, highlighting a radical contextual and relational approach to understanding moral good in health care. Where traditional biomedical ethics emphasizes independence, universality, and legalistic protections, care ethics seeks interdependence and relational responsibility (Metz and Clark 6). In practice this means that while biomedical ethics might frame informed consent as the isolated decision of an autonomous subject, care ethics views consent as dialogue. It is a process in which vulnerability, trust, and the voices of family and caregivers converge. Traditional biomedical ethics is more intended to secure patient rights to protect dignity, while it is through care ethics that patient dignity is more likely to be actualized.

Feminist ethicist Carol Gilligan challenged the dominance of justice-as-rule in her book *In a Different Voice*, arguing that moral reasoning is also rooted in care, responsiveness, and attentiveness. She championed the idea of listening and acknowledging the voices of women and their autonomy in what was a male-dominated world in 1970's psychology. This evolved into the theory of "ethics of care" based on responsibility to self and others through gender-neutral relationships (Josselson 121-22).

Nel Noddings described care as a "web of relationships" (Noddings 9) that define meaning itself. While Joan Tronto extended this vision, showing that care is social and requires us to draw on relationships to facilitate caring actions (Fisher and Tronto 52). She argues that the health of a democracy depends upon the recognition of care as a shared social responsibility, recognizing that humans, while autonomous, should also be seen as "vulnerable and interdependent" (Tronto "Caring" 280). These voices collectively reveal that ethics is not only about choice but about relation, not only about principles but about presence. This is what leads to the preservation of human dignity.

Canadian psychiatrist, academic, and researcher Harvey Chochinov demonstrated that dignity is especially central at the end of life. His work on dignity therapy argues that when patients perceive their dignity to be undermined, they are more likely to experience hopelessness or even the desire for a hastened death. Conversely, when dignity is actively preserved through "recognition, respect, and relational presence," patients report an increased sense of meaning, coherence, and peace (Chochinov et al. 5520).

It continues to be that many physicians remain undertrained in end-of-life care, focusing on diagnosis and treatment rather than relational presence and communication (Meier et al. 580). The biomedical model continues to prioritize cure, often leaving little room for dialogue about meaning and closure. Nurses, by their professional orientation, are encouraged to form relationships with patients, a dynamic sometimes described as "professional intimacy" (Antonytheva 155).

This intimacy reflects the relational nature of nursing practice. The tension between expectations of professional boundaries coupled with demands for empathetic closeness create ethical strain, particularly in hospice, where relational presence is at the heart of care. Hospice nurses cannot simply withdraw into technical distance without violating the dignity of their patients, nor can they fully open themselves without risk of moral injury when systemic forces obstruct ethical care.

Hospice Nurse Moral Distress

According to a Gallup Honest and Ethics Poll, Nurses continue to be voted the most trusted professionals in the United States for the 23rd year in a row (Walker 1). They also remain among the most impacted by the ethical failures of health care institutions. The practice of nursing is, at its core, a moral endeavor grounded in justice, accountability, and advocacy (Jones-Bonofiglio 101). Hospice nurses hold this role of patient advocate particularly close, as the dying are among the most vulnerable populations on the health care continuum. The *Code of Ethics for Nurses* underscores the right to patient self-determination and emphasizes the importance of end-of-life decision-making (American Nurses Association 4).

For hospice nurses, this work carries an added complexity: they must assist dying patients in navigating not only medical choices but also the existential reality of life's end. To advocate for a patient in this context is to safeguard not only their physical comfort, but also their relational and spiritual wholeness. This is where clinical meets the existential.

Moral distress in nursing is multifaceted and complex. Andrew Jameton first defined it in 1984 as "the inability of a moral agent to act according to his or her core values and perceived obligations due to internal and external constraints" (Jameton 6). Later scholars, including Ann Hamric, emphasized how this distress lingers, leaving a "residue" that affects the nurse long after the immediate event (Epstein and Hamric 322). Not only must the causes of nurse moral distress be mitigated for the health and safety of the nurse, but also for the ongoing quality of patient care.

The cost of allowing nurses to suffer in silence is not only fiscal; it is moral. Valuing health care practices within a system supported by highly skilled and morally attuned practitioners is a societal obligation far beyond the needs of a business. Moral distress signals not simply burnout or fatigue, but a large gap between the deeply held ethical commitments and the structures that constrain them, signifying an underlying systemic problem (Ulrich 21). Left unaddressed, this gap erodes not only the nurse's professional integrity but also the patient's experience of dignity at the end of life.

Carlo Leget, a scholar of ethics of care and end-of-life ethics, argues that dignity at the end of life emerges within relationships of care that surround the increasingly vulnerable person. Dignity will emerge or be diminished within a network of caring relations between patients and professionals, within families and close friends, and through the dying's continued capacity to care for others in small but meaningful ways. In this sense, dignity is not an individual achievement but a relational one, upheld in the *between* of human connection, particularly at the end of life (Leget 947-51).

Hospice nurses, in this light, occupy the liminal space between institutional authority and patient vulnerability, and it is precisely in this space that the preservation or diminishment of dignity is decided and where moral distress can take hold. To confront moral distress, then, is also to confront the very structures that define how we allow people to die. In Martin Buber’s terms, whether the dying are met as Thou or reduced to It determines whether dignity is preserved or denied (*Buber* 78).

METHODOLOGY

“The important thing is not to stop questioning. Curiosity has its own reason for existing.
One cannot help but be in awe when one contemplates the mysteries of
eternity, of life, of the marvelous structure of reality.”
— Albert Einstein

This dissertation employs a unique, multimodal, apophatic approach that integrates literature review, lived experience, and wonder to attend to what cannot be fully captured through explicit analysis alone. I seek to contribute to a newer lens of qualitative inquiry, one that acknowledges the phenomenological tradition toward the aforementioned mysterious and contemplative dimensions of death care, where relational knowing and ethical attunement replace detachment and analysis.

Concepts such as vulnerability, autonomy, dignity, and distress sometimes resist naming, demonstrating a need for an approach that honors what is beyond words. Spoken language is what distinguishes us from other life forms. As humans, we so often feel a need to fill silence with words. We are not comfortable with silence. It is in this silence that we may find the meaning we seek.

Literature Review Through the Lens of Martin Buber

Martin Buber (1875-1965) was a Jewish philosopher best known for his work on relational philosophy; the concept that human life is defined by the quality of our relationships with others, nature, or God. His *philosophy of dialogue* provides a perfect lens to understand the literature on the relational dynamics necessary for ethical end-of-life care and the assurance of human dignity. This lens also provides sound support for the understanding of nurse moral distress when relational death care is compromised.

In this methodology, Buber’s dialogical philosophy informs how the literature on dignity and moral distress is approached rather than serving as a theory to be applied. His distinction between *I–Thou* and *I–It* relationships functions as a relational lens through which ethical and clinical scholarship is read, with attention to how patients and caregivers are treated as either relational subjects or as objects to be managed.

Buber distinguishes between two types of relationships. There are the ***I-Thou*** and the ***I-It***. The I-Thou is authentic and reciprocal in nature. Here each person recognizes the *other* as a whole, worthy of respect and understanding. Whereas the I-It occurs when the Thou is transformed or objectified and treated like a thing or concept. In the context of death care, the distinction between I-Thou and I-It relationships is ethically and existentially significant.

An I-Thou encounter between a hospice nurse and their patient creates a shared space in which presence and ethical responsibility grow. This relational recognition is critical for preserving dignity and personhood, while also allowing for meaning-making by the dying. If a dying patient is not approached as Thou but treated as an It, their personhood is objectified, impacting and often diminishing ethical care. This, in turn, often causes moral distress for the hospice nurse.

Relational vulnerability is central to Buberian philosophy, as well as hospice nursing. Ethical care demands that the nurse also enter a place of vulnerability and openness, risking emotional exposure while still providing care. By doing so, the nurse creates a climate of trust, allowing the dying patient to feel safe in expressing their own vulnerability. This mutuality serves to support the patient in navigating the ambiguous dying role while seeking to maintain dignity and closure. The hospice nurse's own vulnerability and commitment to relational and ethical care can be a potential source of moral risk. The hospice nurse embodies the I-Thou and seeks to combat the depersonalizing tendencies of medicalized death care.

Buber's core idea is that the *Self* or *Being* is formed in relation, not in isolation. Who we are (identity) is established through our wondrous encounters with the world. "Buber's sense of wonder emerges precisely in the space where the subject does not seek to possess or define the other, but to dwell with them in an openness that precedes understanding" (Hansen et al. "Wonder*"* 22). This dwelling resides in the space of wonder.

Patient autonomy and informed consent, for example, are commonly viewed as the rights of an individual considered apart from others, but research demonstrates that meaningful end-of-life care and decision-making depends upon communication and egalitarian relationships (Olthuis et al. 29), and as such, should be understood as relational rather than strictly individual.

Buber's dialogical philosophy strengthens this view: there is no isolated I, only I–Thou or I–It. In health care, the distinction is stark. I–Thou encounters preserve dignity by honoring the patient as a person; I–It encounters reduce the patient to a diagnosis, a body, or a problem to be managed.

Unknowing through Apophatic Inquiry

Qualitative and phenomenological research seek to understand the lived experiences and meanings that shape human existence. Some aspects of end-of-life care and moral distress resist full articulation through language or analysis alone. Experiences of silence, uncertainty, and moral weight often exceed what can be easily described. For this reason, apophatic inquiry offers a complementary approach. It creates space to attend to what remains beyond explanation.

Merel Visse's aesthetic-apophatic phenomenological approach positions self-reflexivity as an indirect, experiential practice that explores experiences that resist direct description. Apophatic inquiry emphasizes unknowing, receptivity, and wonder, allowing meaning to emerge through aesthetic *engagement* rather than linear analysis. By "living the questions" instead of resolving them, this approach supports ethical attention to the morally complex aspects of lived experience, making it particularly relevant for qualitative research concerned with dignity at the end of life and the resulting nurse moral distress that can result when the ability to ensure such dignity is fractured (Visse 1-9).

I examine the case of a former hospice patient, Althea (a pseudonym) whose seeming loss of voice led to my suffering from moral injury. This lived experience resulted from a fracture in relational death care. It demanded a deeper unfolding in ways that exceed language, logic, and established categories of knowing or understanding. This case uses a single personal experience for its learning potential rather than its representativeness (Stake and Visse 12). It provides a concrete relational context in which care, dignity in death, and moral distress can be examined as lived ethical experiences, aligning with an apophatic approach. Because this experience continues to carry moral weight, it invites ongoing reflection, pause, and openness, central to the features of apophatic methodology.

Apophatic inquiry serves not as an alternative to rigor, but as a rigor of a different kind: one that resists premature explanation and instead attends carefully to experiences that exceed conceptual clarity. It is especially suited for exploring nurse moral distress, vulnerability, and the relational nature of end-of-life care. Such inquiry values humility of what cannot be fully known, mirroring the stance of the hospice nurse who must often *live* with suffering rather than *resolve* it. Its strength lies in allowing meaning to emerge through presence, wonder, and unknowing.

The arts and humanities have long recognized wonder as the beginning of ethical and perceptual transformation. Wonder "invites learners to slow down, to dwell in uncertainty, and to appreciate complexity without the need for resolution" (Zheng 256). This orientation parallels the apophatic stance of unknowing central to my inquiry and quest for healing.

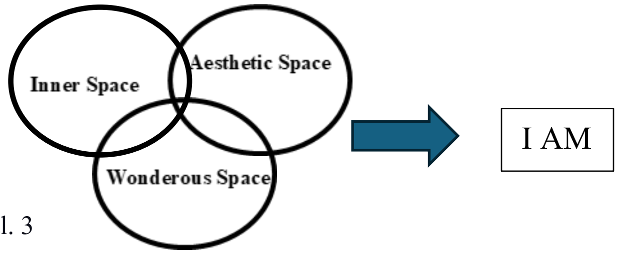
The Triad of Apophatic Space

Central to the mystery of an apophatic model is the "triad of space" - the inner space, the aesthetic space, and the wondrous space. Apophatic spaces are not designed as frameworks for problem-solving. Rather, these spaces, particularly the *wondrous space*, represent an interplay of awareness that invites a deeper immersion in the phenomenon, in this case, Althea's story and my experience of moral distress. Wonder has been defined as an "emotion or state of consciousness in which one's attention is fixed on phenomena beyond one's comprehension" (Zheng et al. 256). Wonder gives permission to not know and to move forward, embracing what is mysterious and without answers.

Alexander Zhang (226) argues that wonder functions both epistemically and morally, offering a way to *know* and *relate* that transcends rational agreement. He writes that wonder provides a way by which we assign the object in question an intrinsic value while quieting self-importance, allowing us to better understand the phenomenon.

Wonder can offset desensitization. Using the arts allows clinicians to see what is overlooked or taken for granted, where imagination helps lead to tolerance for ambiguity and increased empathy in medical care (Zheng et al. 258).

These quiet forms of care are not only ethically significant, they are often more meaningful than medical interventions. Drawing on H. M. Evans' sustained body of work on wonder in medicine, I apply apophatic inquiry to engage in what he calls "special attentiveness" to "transfigure" (Evans "Wonder" 127) my encounter with moral distress as something with which I no longer need to identify myself. He reframes the moral gravity of medicine as also grounded in attentiveness to shared embodiment and finitude (Evans "Medicine" 97).



Visse, et al. 3

The ***inner space*** of apophatic inquiry refers to the internal realm where we listen deeply to our feelings. These feelings are shaped by a blend of lived experiences and the beliefs about what we hold to be true. Entering this contemplative space requires an open, nonjudgmental stance, allowing us to move beyond the limitations of language and to remain present with what arises. Consider it a place of contemplation or meditation on an experience that resonates or disrupts, while quietly reshaping our understanding of ourselves and our situation.

The ***aesthetic space*** offers a way of exploring experience through non-verbal, sensory, or symbolic forms. This space is about the "creative and receptive activity of resonating with a phenomenon” (Visse et al. 5). It invites us to explore what it is we sense in our bodies as ways of knowing and gathering knowledge, rather than strictly an intellectual engagement.

Curt Cloninger’s work on apophatic practices supports the inclusion of visual work as a parallel apophatic practice that holds space for what cannot be adequately expressed through narrative or theory alone (Cloninger 15–17). He describes apophatic visual practices as operating through withholding and refusal in order to preserve ethical meaning rather than resolve it.

Through this space, I access a different kind of understanding, one grounded in imagery, emotion, and textures supporting deeper inquiry into my questions. Drawing from various Major Arcana cards of the Tarot, I chose watercolor to creatively express the apophatic aesthetic space identified in Part III as contributing to my moral distress. Nora Xu, an independent artist, educator, and author whose reflections on watercolor as a medium of compassion resonate closely with my own use of this artform within apophatic inquiry. She emphasizes watercolor’s "unpredictability, fragility, and impermanence" as qualities that mirror the nature of human experience (Xu 33-34).

The final ***wondrous space*** is a place for reimagining or even allowing for the rewriting of an experience. Instead of providing answers, it encourages questioning and reflection. This space invites us to embrace the mystery in our experiences. Working within this model afforded me the time, patience, and trust necessary to remain present with whom I am in relation to the moral distress I experienced in 2012, while also honoring my encounters with Althea.

Unfolding

Unfolding refers to the reflective process through which insights from the inquiry gradually become visible through my artwork. After engaging with the experience of moral distress through the inner, aesthetic, and wondrous spaces, this stage allows for a careful return to the experience in order to consider what has been revealed. Rather than seeking definitive conclusions, unfolding acknowledges that meaning often emerges slowly through sustained attention and reflection.

My artwork functions not as illustration but as a form of inquiry in its own right. Watercolor became a way of revisiting the experience from a different vantage point, allowing elements of the encounter that were previously unarticulated to surface. It allowed me a creative space for reflection that was not limited to discursive language. In this way, unfolding becomes a continuation of the apophatic, allowing for gradual insight rather than forced explanation.

BEARING WITNESS: THE CASE OF ALTHEA

"There may be times when we are powerless to prevent injustice,

but there must never be a time when we fail to protest."
- Elie Wiesel

Introduction

What follow are my personal narrative along with a true nursing case from my hospice practice. By recounting this case, I situate my dissertation not only in philosophical and theoretical frameworks, but in lived experience, and their dialectic connection. My narrative shines a light on moral distress and institutional barriers that hospice nurses often face when relational care and patient dignity are undermined by medicalized practices. This is my account of how moral injury, perceived institutional betrayal, and the profound ethical distress can emerge when one's core values are rendered incompatible with the system in which they work.

Moral Inheritance

As stated, the practice of nursing is a moral endeavor (Jones-Bonofiglio 101). For me, this moral imperative was instilled early. I was raised by parents whose lives were guided by a deep commitment to justice and responsibility. These values were not rooted in religion or ideology, but in an uncompromising sense of doing what was right.

My moral inheritance is complex. My father, a high school social studies teacher and former teachers' union president, modeled advocacy for others. He negotiated contracts late into the night and believed in the power of collective voice. He introduced me to nonfiction, Walter Cronkite, political discourse, and the idea that being white carried privilege. In his view, some politicians served the rich, while others served the poor. It was that simple. Forgiveness was his proverbial middle name and he believed in presenting options and allowing others to decide.

My mother was a first-aid volunteer for three decades and dreamed of becoming a nurse like her own mother. The polar opposite of my father, she was deeply critical, emotionally volatile, and often resentful. She had an unforgiving sense of right and wrong. She took pride in leading during emergencies and relished the adrenaline, though more from a place of control versus compassion. I came to believe that caregiving aligned with such a temperament. Not necessarily true.

Despite these contradictions, I carried a strong moral blueprint into adulthood. After earning a degree in philosophy, which complicated my desire for moral clarity, I entered corporate management in telecommunications. There, I negotiated a world of efficiency metrics and marketing requirements. But something was missing.

The events of September 11, 2001, and my service during that time as a juror on a medical malpractice case involving a patient death, served as turning points. Suddenly, the perceived meaninglessness of my work became unbearable and I began to reconsider my future. By January 2002, I had enrolled in my county college to pursue a degree in nursing.

Hospice Calling

I completed my nursing degree in three years while working full-time. By 2005, I was divorced, remarried, and entered clinical practice, naively hopeful to care for others in a way shaped by both personal values and academic training. But I quickly discovered a profound disconnect between what I believed nursing should be and the realities of practice. Working in long-term care facilities and hospitals, I felt pressured to prioritize tasks over relationships. Physical assessments were reduced to vital signs and pain scales. Time for presence, listening, witnessing, and connecting was seen as inefficiency. Nurses were treated as assembly-line laborers, tasked with reassembling human beings quickly enough to send them back out, only to be broken again. While I fully appreciated the business needs in health care, it was nonetheless demoralizing.

In 2006, I reached a breaking point. After escalating concerns about unsafe patient care and nurse bullying on my unit, I was offered a transfer by a perceptive HR manager. I chose hospice. It seemed like the one space in health care where time, dignity, and relational presence were still valued. For the next six years, hospice gave me a sense of purpose I had not felt elsewhere. I could advocate for patients, support families, and bear witness to death as a natural process, not something to be fought or feared, but honored. I found a rhythm in the work, and a tribe of like-minded clinicians.

Fading Away

The case that drives this dissertation centers around a hospice patient I have called Althea - a name that means "with healing power." Althea, elderly and living with her son, was dying of cancer when she fell at home and fractured her arm. Though hospitalized, she remained under hospice care, making me, as her RN case manager, responsible for her care plan.

During my first hospital visit, joined at her bedside by the hospice social worker and clergy, Althea expressed a clear desire to return home. I assured her I would advocate for her and consult with her physician. In my mind, there was a possibility of providing her with pain management at home, knowing that this fall would be a catalyst for faster decline in her health. But when I called her physician from the nurses' station, his response was chilling: "Look, she's not going home. I'm going to put her on a drip and let her fade away." By drip, I knew he meant a continuous intravenous infusion of morphine. By “fade away” I also knew what he meant and time came to a halt.

I do not recall how I responded, only that I immediately called my hospice manager. Her reaction was, "Oh no. Not another one," somehow implying this was a common occurrence. I remained dumbstruck. I proceeded to document the physician’s statement verbatim in Althea’s medical chart and left the hospital shaken, unable to continue my day. I pulled my car over to the side of the road and called the office in tears. Whomever I spoke with expressed concern for my well-being, but no further solution to the situation.

I returned the next day to find Althea unresponsive on the morphine. She died that night. On the following day I called her son to give my condolences. He expressed to me his confusion as to why his mother had died so suddenly. Trying to find the right words, I recommended he call her physician to ask him for details about her care. To this day I do not know what transpired. I failed to reach out later due to a fear of further entanglement in any legal aspects of the situation. I soon left for a scheduled family vacation to the Grand Canyon.

Aftermath

Upon returning from vacation, more numb than rested, I requested a meeting to obtain clarity and closure to the question of informed consent for what amounted to palliative sedation. What I received was an inadequate meeting in a small windowless conference room with my manager, the social worker and clergy who were with me at Althea’s bedside, and a physician who *stood in* for Althea’s physician. Not only did she provide second-hand information, she attended the meeting via telephone. I instinctively knew where this was headed.

My concerns were dismissed, with this physician claiming that consent had been obtained by phone from Althea to her physician. I questioned the validity of such consent given her age and mentation at the time, and questioned why her son was apparently not contacted. I went on to press the issue, standing up and exclaiming “bullshit!” to continued insistence that consent was obtained. What followed was a rapid unraveling. My manager proceeded to accuse me of having “anger management” issues.

What remained after the meeting was not only sorrow but a deep moral wound. The experience moved beyond momentary moral distress into what scholars characterize as *moral injury*: the psychic and ethical harm that occurs when one witnesses, or feels complicit in, actions that violate one’s fundamental moral beliefs (VanderWeele et al. 2). My subsequent treatment by supervisors including the dismissal of my feelings, in-person monitoring of my work out in the field, and the implication that I was the problem, felt like institutional betrayal. The organization I had trusted to support ethical care (and me) instead appeared to side with the authority that I believe had silenced Althea’s agency in the first place.

Institutional betrayal compounds moral injury as it removes the possibility of emotional repair. When the structures designed to uphold standards and protect patients fail those who raise concerns, the moral harm is deepened and prolonged (Brewer 1083). The aftermath was not just an unanswered question about a single clinical and legal decision. It was a rupture in the trust that should exist between caregivers and the systems that govern them. I was left with no other recourse but to resign.

PART II: KNOWING

CHAPTER 1

THE MORAL COST OF RELATIONAL DEATH WORK

"Those who do not have power over the story that dominates their lives, power to retell it,
to rethink it, deconstruct it, joke about it, and change it as times change,
truly are powerless because they cannot think new thoughts."
− Salman Rushdie

Introduction

Current literature highlights that moral distress in nursing has a primarily psychological and moral component. It is the pain of knowing what care for the dying should look like, all along being unable to provide it. It develops when medical interventions imposed feel suspect or even wrong, or when a nurse's own instincts are dismissed in the name of protocol. This kind of distress is not just emotional; it is ethical. It lives in the space between what we believe is right and what we are allowed to do, and it comes with a cost.

The term moral distress was first defined by Andrew Jameton in 1984 as "the inability of a moral agent to act according to his or her core values and perceived obligations due to internal and external constraints" (Jameton 6) (Ulrich et al. 20). Ann Hamric has since expanded on this definition, describing how moral distress lingers as "moral residue," leaving lasting wounds that influence both the professional and personal identity of the nurse (Hamric 322).

For hospice nurses, this distress is particularly acute, as the work demands not only clinical expertise, but sustained relational presence with those who are dying. Hospice nursing requires relational intimacy, solitude of field work, and a lack of institutional support. When systemic forces such as hierarchical medical authority, lack of communication, or institutional silence block ethical care, nurses endure more than frustration. They experience what ethicists have called moral injury or even institutional betrayal, violations of trust that strike at the very core of caregiving (Rushton and Boston-Leary 112).

Moral distress, therefore, should not be reduced to terms such as burnout or compassion fatigue. It must be recognized as an existential threat to nurse well-being, along with that of patient and family dignity. In Martin Buber's dialogical philosophy, ethical care requires an I–Thou encounter, where patients are recognized as whole beings. When medicalization or paternalism reduces the patient to an I–It object of treatment, dignity collapses, and with it, the moral integrity of the nurse tasked with safeguarding it (Buber 78). To address moral distress is thus not only to care for nurses but to care for the very possibility of relational, dignified death care.

This chapter will examine how moral distress shows up in those who care for the dying, tracing its definitions, sources, and consequences. It will argue that moral distress should not be mistaken for individual weakness but understood as a systemic alarm bell, signaling how care for the dying too often falls short of the relational model it ought to be.

Literature Review

Defining Moral Distress

Ann B. Hamric is the associate dean of academic programs and a professor in the School of Nursing at Virginia Commonwealth University in Richmond, VA. She defines moral distress as occurring when "a person's moral integrity is seriously compromised, either because one feels unable to act following core values and obligations or attempted actions fail to achieve the desired outcome." What remains with a nurse who experiences moral distress is the "lingering" effect or "residue" that lives in the body as a moral injury or trauma (Hamric 322). The experience continues to come and go, often compounded by other similar experiences (Wallis 19).

There is varying terminology to define moral distress, including moral injury, moral damage, inner conflict, betrayal, or injury to the soul. The experience of moral distress appears subjective to the individual and how they perceive events. What all these definitions have in common is the perceived violation by another of firmly held moral beliefs that causes injury in some form. This violation can cause differing degrees of psychological trauma (Hodgson and Carey 1212-13).

It is the very nature of caring relationships as being the "embodiment of interpersonal commitments which generates the potential for moral distress.” These commitments are intentional and continue until the caregiving needs are met, discontinued, or assumed by another. When external factors unexpectedly disrupt this commitment to care, it can cause distress for the nurse, as the relationship and commitment might remain unfulfilled (Walsh 616-20).

The Relational Nature of Distress

This perceived break in the caring relationship and exposure to suffering can create certain feelings, including shame, loss of trust in self and others, spiritual conflict, guilt, and loss of meaning. Secondary symptoms often manifest as depression, anxiety, anger, and rumination on the original conflict, social or relationship problems, substance abuse, or even suicidal ideation (Vanderwelle 2).

Native Americans believe that every time we heal another, a part of ourselves is given away, including the ability to empathize. If this happens often enough, caregivers will also require some level of healing, which can only come from empathy by another. They become a type of *wounded healer* (Stebnicki 3). The Native American concept of the wounded healer describes modern-day compassion fatigue and may result in the reduced ability to empathize, stemming from the healer's need to be made whole again.

Nurses are presumed experts in care and hold significant power to assist in healing. Without empathy, their power remains untapped, rendering them less useful in the caring relationship. So begins the pathway of apathy leading to a decline in safe, quality patient care. By design, the proximity of the hospice nurse to the patient exemplifies the relational aspect of caring. It is actualized as a "web of care" (Noddings 9), for meaningful dialogue and attention to pain and suffering that extend beyond what traditional medicine can address. This space is where the moral and ethical dilemmas involved in dying are addressed with empathy, responsibility, and a commitment to existential needs.

It is a space of mystery where the hospice nurse is privileged to be. Joan Tronto’s ethics of care further illuminates why hospice nurses are so vulnerable to moral distress. She identifies four interrelated phases of care: 1) caring-about - attentiveness to another’s need, 2) taking care of - accepting responsibility to respond, 3) care-giving - competently providing care, and 4) and care-receiving - how care is or the experience by the one cared-for (Tronto “Caring”17-18) (Tronto 16-17).

Moral distress can arise when any of these phases are obstructed. A nurse may be attentive to suffering, while simultaneously dismissed by leadership (caring about *denied*). They may feel a deep responsibility but lack institutional authority to act (taking care of *denied*). Or they may be prevented from carrying out competent care due to resource constraints or hierarchical power (care giving *denied*). Most devastatingly, the patient’s voice may be silenced, preventing genuine responsiveness (care receiving *denied*). These breaks in the relationality of care leave the nurse holding not only professional frustration but the moral wound of witnessing dignity *denied* in the very space where it should have been safeguarded.

Sources of Moral Distress

A 2013 study comes closest to clarifying a significant reason that nurses often experience moral distress. It was found that nurses who possess a higher level of authority are often associated with increased moral distress. By nature of the specialty, hospice nurses are those nurses; alone in the home acting on skill and intuition. Ethical and clinical dilemmas need to be communicated to patients and families in ways that are understandable, tactful, and still direct.

Nurses must also possess the ability to make informed decisions in challenging situations that involve personal and existential considerations. This decision-making extends to treatment choices and requires the strength of character to address differing opinions about treatment options from both physicians and family members (Burston and Tuckett 315). This higher level of authority supports the commitment theory of Walsh

(2025) and the duty to care as factors that contribute to an increased risk of experiencing moral distress.

Further review of the literature uncovered other various sources of nurse moral distress, including harm to patients in the form of pain and suffering and the treatment of patients as objects when meeting institutional requirements. This is Buber's I-It relationship, when personhood is overshadowed by medical prolongation of dying, lack of autonomy, fiscal containment, and personal factors such as lack of confidence or fear (Corley 639) (Jones-Bonofiglio 7). These exemplify the transactional nature of health care in America and its distance from patients being *cared-about* versus *cared-for*.

An additional stressor for nurses is their inability to express or take concerns to the proper institutional authority. There is a particular culture of silence that exists in nursing, causing a sense of isolation. Nurses often shy away from sharing these ethical situations or dilemmas for fear of retribution or lack of moral competency and courage (Jones-Bonofiglio 126).

Moral distress specific to hospice nursing is not an area that has seen much research. Nor have the psychological responses to nurse moral distress been explored enough (Corley 639). There is an inaccurate assumption that once an individual qualifies and signs up for hospice care, they fully understand and consent to the final phase of their care. The reality is most are not physically or emotionally ready for the journey before them, which is preparing for death. Nor are their families.

Patients often come to hospice by way of institutional palliative care, which can be fraught with biomedical thought processes and tasks (Olthuis 29). Another study conducted in 2023 found that a major stressor for hospice staff was the burden of "having to give bad news” (Papworth et al. 598). This begs the question; why are physicians or other health care professions not addressing this unwelcome news prior to beginning the hospice process?

Enter a hospice nurse with an entirely different clinical skill set and visceral awareness of the upcoming loss of personhood. With a heightened sensitivity to patient advocacy and justice, it could be argued that hospice nurses also possess a greater awareness of what constitutes genuine care. This final phase of life certainly requires technical and medical knowledge of the dying process and how to manage the physical symptoms. It is the esoteric care of the dying that separates the hospice nurse from other nurses. The pressure on the hospice nurse to define and ensure whatever the patient feels is a good death weighs heavy.

The hierarchical relationship between physicians and nurses is another factor contributing to moral distress in nursing. Nurses often perceive themselves as having powerlessness or "accountability without authority" when addressing differences in opinion or the inability to speak up against a physician's plan or actions. Often, the nurse is faced with the choice of overstepping the physician and acting in the best interest of the patient or waiting for the physician to act while the patient suffers (Burston and Tuckett 315-16).

Indeed, not every ethical dilemma or issue leads to moral distress. Moral distress is, again, a personalized experience that can result from an ethical question at hand, along with other factors involved in the situation. Individuals differ in their values, education, beliefs, and past experiences, all of which influence their interpretation of the ethical dilemma. What truly compounds the distress is the frequency of ethical dilemmas and the lack of attention and research associated with the potential outcomes (Jones-Bonofiglio 2).

Psychological and Emotional Consequences

The insecurities that evolve from a feeling of moral inadequacy or defeat can be expressed externally to peers (bullying) as a way of self-protection or "getting them before they get me" mentality (Jones-Bonofiglio 101-2). Nurses can experience post-traumatic-like symptoms when struggling with ethical or moral dilemmas. These can include emotional or physical changes, nightmares, avoidance of similar situations, repetitive negative thoughts, reliving the experience, feelings of isolation, loss of sleep, and emotional lability.

Prolonged stress can cause a reduction in accessing old memories and the processing of new ones. Decisions tend to be more impulsive, while behaviors such as jumpiness, feeling on edge, or irritability are common. Without proper interventions, individuals can become progressively numb, feel depressed, and withdraw from interactions with others (Benjamin et al. 10-14). Feelings and behaviors such as these can have a direct impact on safe patient care, as the nurse may not be at the height of their mental acuity.

Hospice-Specific Stressors

Hospice nurses uniquely experience emotional trauma when faced with ethical end-of-life care. Exposure to a traumatic or stressful event is the initial diagnostic criterion for Post Traumatic Stress Disorder (PTSD). Repeated exposure and feelings of moral distress can lead to Secondary Traumatic Stress (STS), burnout, or compassion fatigue (Figure 1). STS is defined as "the stress resulting from helping or wanting to help a traumatized or suffering person" (Arnold 149-51). There can be no denying that each hospice patient faces a once-in-a-lifetime form of suffering, sometimes physical but almost always existential.

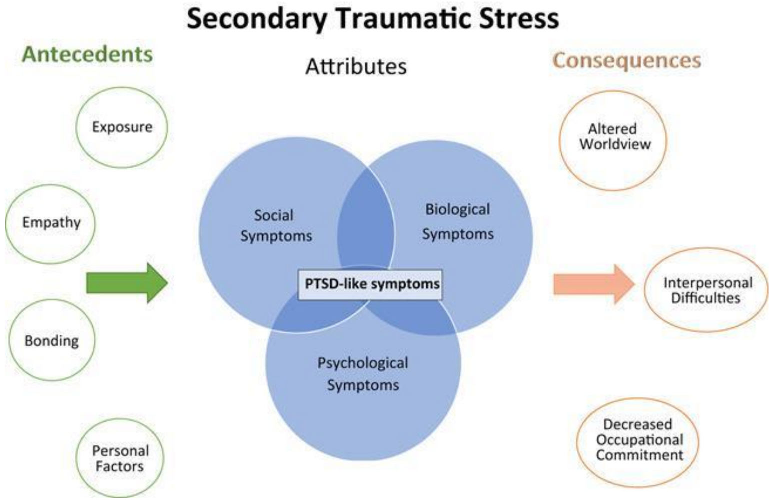


Fig. 1. Concept map of secondary traumatic stress. Source: Arnold 150.

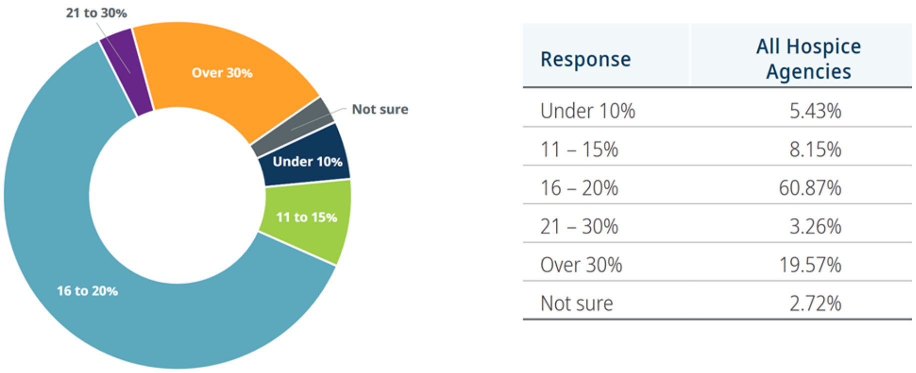
Hospice nursing is unique, as nurses are alone in the field visiting patients where they reside. Between patients, time spent in cars is reserved for documentation and mental redirection in order to be fully present for the next patient. Nurses need to explore ways to compartmentalize each visit. Sometimes, the stressors must be suppressed to keep moving forward, day after day. These suppressions compounded can eventually erupt.

A small pilot observational study conducted in 2022 examined the well-being and turnover intentions of twenty-five hospice interdisciplinary team (IDT) members over a three-month period. One of the key findings was that IDT members demonstrated low levels of overall well-being at baseline, with many already at risk of distress. Compassion satisfaction was high, and burnout and secondary traumatic stress were low. After three months, compassion satisfaction was found to decrease by 5%, while burnout increased by 17%.

Additionally, turnover intent at baseline was zero, with no participants intending to leave their current employer. By the end of the year, it was found that one employee had already left, while another was considering doing so. While this was a limited study conducted on a single IDT, it did highlight the need to improve well-being and reduce burnout among hospice workers (Schneider et al. 3-5)

The 2022 National Healthcare at Home Best Practices and Future Insights Study found that, among the 1,000 hospice agencies surveyed, nearly 60% of respondents reported turnover rates of 16-20%. Moreover, almost 20% had turnover rates over 30%. Unfortunately, this data does not distinguish between the types of staff, so the amount of hospice nurse turnover is unknown. The best practice metric used by the organization is overall turnover rates of less than 15% (Doak 47). This benchmark is not being met (Figure 2). Additionally, salary/pay appears to be the primary reason for staff members leaving. Unfortunately, the survey did not include a question that specifically addressed ethical practices.

Hospice Staff Attrition



Response	All Hospice Agencies
Under 10%	5.43%
11 – 15%	8.15%
16 – 20%	60.87%
21 – 30%	3.26%
Over 30%	19.57%
Not sure	2.72%

FIGURE 2: The National Healthcare at Home Best Practices and Future Insights Study of 2022

Silence, Stigma, and Organizational Barriers

Communication is vital in complex health care environments where diverse professionals collaborate to achieve shared objectives. Within the hierarchical structure of health care, silence can pose hidden risks to patient safety. Research conducted in Turkey has shed light on how many nurses feel compelled to remain silent on ethical dilemmas due to administrative challenges. As a significant part of the health care workforce, nursing voices are crucial for promoting improvements in the quality and safety of care, as well as enhancing our work environment.

This Turkish study identified three key themes associated with silence: fear, a silence climate, and disengagement. The fear theme encompassed several subthemes:

1. The apprehension of being labeled as a troublemaker
2. Concerns over potential financial repercussions

3. The reluctance to admit one's own limitations or lack of knowledge (Yalçın, et al. 1-7)

The concept of employee silence was explored in response to perceived injustice, examining its complexities, forms, and implications for organizational behavior and human resource management. Two forms of silence were introduced: quiescence (referring to passive silence) and acquiescence (which involves a more active form of compliance). Quiescence is a state of conscious discomfort and disagreement even objection with circumstances, where employees are ready to voice their concerns, but may not. While acquiescence involves the acceptance of the situation and a lesser awareness of alternatives or solutions to the situation. These employees are even less likely to use their voices (Pinder and Harlos (333-38).

Silence can also be influenced by fear. In these cases, employees feel open communication or criticism is not welcome, especially in the presence of power dynamics, suppression of conflict, hierarchical settings, and a focus on production over human relationships. Gender also appears to be an influence on the likelihood of speaking up, finding that women are less likely to make their concerns known. Notably, as of 2022, men still only make up less than 11.2% of all licensed practical nurses, registered nurses, and nurse practitioners; an indication on the influence of gender on a culture of silence (Smiley et al. S12).

Faced with inaction by an employer or organization to complaints or recommendations, the silence deepens. This deepening silence often forces us to find our own ways to cope. One way is through cognitive dissonance (Jones-Bonofiglio 91). Sometimes, we rewrite our narrative to manage the pressures of moral and ethical conflicts. In essence, we are suppressing the stressful situation to focus on the tasks at hand, leading to the creation of a protective wall that shields us from involvement in the caring relationship with the patient. Again, this is detrimental to meaningful and safe delivery of care.

Ironically, the health care profession has done much to assist the public in decoupling the terms mental illness and mental health while failing to help its practitioners do the same. Nurses continue to feel stigmatized for admitting or reaching out when the job's stressors become overwhelming to navigate. This stigma, defined as a "social process characterized by exclusion, rejection, blame, or devaluation that results from the anticipation of an adverse social judgment" likely contributes to the decision not to seek help or support for feelings related to moral distress (Rushton and Boston-Leary 7).

In 2019, sixty-five percent of nurses were found not to seek mental health assistance (Rushton and Boston-Leary 7-8). This fear of mental health or trauma stigma is a compounding factor as to why nurses are reluctant to speak up about perceived moral or ethical practice dilemmas, leading to even more personal reasons for staying silent. Being labeled as having anger management problems is quite an effective way to gaslight a nurse into thinking they are the ones with the problem.

This stigma has also led researchers to focus more on terms or experiences of burnout or depression rather than the reality of symptoms exemplified in experiences of trauma or PTSD. A systematic review conducted in 2020 examined the impact of supportive relationships on the risk of traumatization among high-risk professionals. Nurses considered high-risk professionals worked in the emergency room, operating room, and intensive care unit. (Geuzinge et al. 2-14).

While death in hospice is certainly an expected outcome, being witness to injustice at the end of life can be traumatizing. This is coupled with the multifaceted, holistic bond created between a hospice nurse and their patient, puts the nurse at an even higher risk for moral distress.

Conclusion

Health care practitioners must approach end-of-life care as an ethical and relational obligation inherent in their humanity. The connection a caregiver feels with a patient can lead to heightened awareness of injustices or obstacles that may hinder a peaceful death. A hospice nurse who has never experienced any level of moral distress while providing end-of-life care should seriously consider whether they belong in this specialty or truly grasp the relational aspect of death care. It is also vital to acknowledge that moral distress may be an inevitable consequence of this work. It is not something that happens to nurses but rather something that naturally occurs in the context of such relational caring. There is a moral cost to knowing and caring, while being unable to act.

Through the lens of Buber, the I-Thou relationship between a hospice nurse and their patient is inherently fragile and can only be entered into with openness. The loss of the I-Thou relationship is a moral loss that comes at a cost to the nurse. The nurse feels this loss in their body as distress, grief, and sometimes lasting injury. Dignity is preserved when patients are encountered as whole beings, so when systemic forces, paternalism, or silence close this dialogical space, both patient and nurse suffer. The patient loses the dignity of being recognized, while the nurse carries the moral cost of witnessing this loss. The following chapter turns from the inner experience of nurses to the broader systemic forces of medicalization that perpetuate these objectifying practices and make the preservation of dignity so difficult.

CHAPTER 2

THE MEDICAL WAR ON DIGNIFIED DYING

“Death has been exiled from everyday life and confined to the hospital,
where it becomes an object of medical intervention rather than a part of the human condition.”

— Jacques Derrida, philosopher (from The Gift of Death)

Introduction

There was a time when dying occurred in the home, among family, with rituals, reflection, and a notable measure of dignity. Today, death more often occurs in hospitals, under the direction of physicians imposing clinical interventions that shape how we experience our final days. Euphemisms such as “failure to thrive” or “debility” frame death as if it were a diagnosis rather than a natural and inescapable human experience. What might it mean to reclaim dying as a process rich with meaning and dignity, rather than a pathology to manage?

This chapter explores how the medicalization of death contributes to the erosion of patient dignity at the end of life. Institutionalization and the business of dying often reduce patients to objects of treatment, stripping them of the recognition and voice that affirm their dignity. Hospice nurses are frequent witnesses to these indignities, bearing the weight of moral distress when their patients are treated as It rather than Thou in Martin Buber’s terms.

By examining these forces of institutional practices this chapter lays the groundwork for a new *bio-relational model of care***.** Such a model affirms that while death involves biological processes, it is not itself a pathology. It is a relational, existential, and moral event in which dignity must be preserved.

Literature Review

The Rise of the Medical Gaze

Medicalization refers to the process of prescribing medical care or intervention for non-medical experiences. The transformation of certain natural phenomena from non-medical to medical is often considered a result of a desire to increase institutional profits, also known as economic medicalization. Medicalization is also a social process with a history of attaching religious or medical reasons for behaviors that may not have been readily accepted by society, such as those leading to crime or delinquency. Many of these “patients” were not sick but instead suffered from their life situations. Science soon replaced religious rationale for human behaviors and disease (Poitras and Meredith 313-15). Addressing the individuals as having an affliction was easier than addressing the reasons for these behaviors, such as the societal issues of poverty and unemployment.

Americans are now living within a health care system that continues to institutionalize medicine as a business model and an answer to much of society's dysfunction, including a cure for death. Michel Foucault, in his book *The Birth of the Clinic,* argued that the modern clinical setting transformed medical practice from a holistic view of the patient to a focus on the body and disease as a localized phenomenon. He described a form of "medical esotericism," where physicians have their own language to address clinical observations. This language is only known to them, placing the physician in a position of power and status over the patient (Foucault 308) (Lantz 64).

Through this *medical gaze*, Foucault argued that doctors were fitting a patient's story into a biomedical framework, filtering out any aspects they deemed medically irrelevant, thereby treating patients as objects by neglecting their subjective experiences (Misselbrook 312). This approach led to a more medicalized rather than relational manner of caring for patients.

Society can also dictate the extent of medicalization of conditions or experiences. Death is rooted in both societal and cultural aspects. Fear of death and dying is a universal phenomenon, and how society addresses and accepts the inevitable will undoubtedly influence how medicine intervenes and takes control. Ironically, it is this such control, or lack thereof, that often define a “good death” (Walters 406). Modern society has denied the beauty of the relational phenomenon of death and dying, contributing to fears of death.

Today’s society is stricken with anxiety when presented with any awareness of death (Lehto and Stein 23). It often looks to the medical profession to help stave off the inevitable, and the medical profession attempts to oblige. Medicalization can also stem from risk-avoidance among clinicians, driven by the fear of being wrong in a litigious society. They practice “defensive medicine.” This risk-avoidance can result in under-identification of terminality and over-implementation of futile interventions (Elton 815-18). Down the line, this often leads to the hospice nurse being the bearer of “bad news,” as previously mentioned, a contributing factor to moral distress.

Institutionalization of Dying

Advances in medicine that provide curative or life-sustaining interventions have served to kick the proverbial can of death down the road even further, allowing more time to deny the inevitable. Medicalization and institutionalization of death care, with a focus on costs and control over what constitutes a good death, have turned hospitals and skilled nursing facilities into places to die. Loved ones are removed from society, causing what Michel Foucault termed a "social death" (Powell 356). Hospice care for the dying comes too late in the health care continuum as patients continue to look for medicine to "do something" about it (Dugdale 5-6).

Physician Perspectives and Emotional Barriers

Patients are not the only ones in denial of death. Dr. Diane E. Meier, MD, the founder of The Center to Advance Palliative Care, concluded that physicians' emotions concerning patient care require further study to address unnecessary interventions and overtreatment due to a physician's feelings of failure to cure or powerlessness in the face of disease. Meier and her colleagues create an overall argument for a more relational approach to addressing chronic terminal illness and dying (Meier et al. 3007-14). Lenzer (19-20) supports this with her research that found "starving off death" to be the physicians' primary goal of care and part of the American medical culture. She expressed that part of the solution involves shared decision-making, where patients and families are afforded the transparency that is often due to fears of malpractice, knowledge gaps, profit-seeking, biased research, and financial conflicts of interest that appear in institutional policy-making.

Nurses who worked with the critically ill in the UK expressed frustration with the lack of skillful death and dying communication between physicians and patients. Nurses Improving Care for the Healthsystem Elders (NICHE) is a geriatric nursing program in the UK that addresses hospital nurse involvement in decision-making and care for older adults. Of the 21,639 nurses who submitted survey responses to the NICHE Benchmarking Service in 2013, 393 specifically responded to open-ended questions regarding end-of-life decision-making (Dillworth et al. e3).

Qualitative themes arose from this study, one of which identified gaps in communication between physicians and patients regarding approaches to terminal prognosis. Conversations about the prolongation of life versus quality of life were lacking, and some nurses expressed that physicians were even dishonest with patients about their prognosis altogether. One nurse wrote, "doctors mislead patients and families as to the possible outcomes of the patients' conditions" (Dillworth et al. e5-e6).

Findings of physician overtreatment and poor communication about death raise the question of medical school educational approaches to chronic disease and other terminal illnesses, and thus their ability to educate patients on the terminal nature of chronic disease. A 2011 qualitative study examined how twenty-one newly qualified doctors in the UK acquire knowledge of end-of-life care during medical school and in their first year of practice. Students lacked exposure to dying patients, and inconsistent curricula between medical schools tended to emphasize medical tasks over holistic assessment.

There was also a lack of application of theoretical knowledge of end-of-life care to real-life patient experiences (Gibbins 391-93). In 2015, George Dickinson conducted a 40-year history of end-of-life medical education in the United States. While the results indicate an improvement in end-of-life education, an average of only fifteen total hours was spent on this topic, and medical school curricula continue to be the primary barrier (Dickinson 560).

Hospice and the Business of Dying

The hospice movement itself can also shoulder some of the criticism for the loss of relational connection to death and dying. Hospice is designed to manage the physical, psychological, and spiritual aspects of the dying process. Hospice care in the United States is also intended as a tool for reducing Medicare costs. The American institution of health care has absorbed hospice and palliative care, whereby it has taken over much of the control of dying from the individual, thus weakening the hospice movement of unlimited support and relational care.

The care model is rigid (Floriani and Schramm 296) and continues to be primarily governed by institutional associations and cost. Interestingly, death denial significantly contributes to global health care costs (Enkin 1277), with 10-30% of US Medicare funds spent on unnecessary interventions each year, ultimately resulting in approximately 30,000 deaths annually (Lenzer 19).

The 2025 daily (per diem) Medicare pay rate for routine hospice patients in their first 60 days is $224.62 (CMS 2024). All expenses for a hospice patient (including hospice staff salaries, medications, durable medical equipment, wound care supplies, and operating costs) are managed by the hospice organization to ensure they not only stay under the $224.62 per day cap for the first 60 days and beyond, but also remain below it to ensure profitability. Such an association of hospice care with Medicare-prescribed cost structures can also lead to a reduction in the relationality of death care, forcing hospice nurses and social workers to be measured by productivity and quantified quality measures rather than the qualitative outcomes of patient and family satisfaction. The time hospice staff can spend in relation with the dying is reduced due to the time constraints imposed by cost containment. Hospice staff often find themselves increasingly unable to address the existential suffering and needs of patients and their families, which can lead to frustration and moral distress (Cabin 5).

Palliative Care and Palliative Sedation

At the foundation of palliative care is patient and family-centered care that emphasizes symptom management to ensure quality of life without hastening death. A patient does not need to be terminal to take advantage of the benefits of palliative interventions. An example would be an individual who suffered a severe motor vehicle accident and continues to have unmanageable or intractable pain. Often confused with hospice care, which requires a terminal prognosis, palliative care does not. Hospice care is a type of palliative care, but palliative care is not limited to hospice care.

The end of a terminal disease process can bring varying degrees of physical and emotional symptoms that are difficult to control, including pain, nausea/vomiting, delirium, shortness of breath, and terminal restlessness. An uncommon and growing end-of-life medical intervention for such intractable or refractory symptoms (persistent or worsening despite aggressive treatment) is palliative sedation, also referred to as terminal sedation. This medical intervention is a last resort for intolerable suffering in the last days of life, as the patient will be rendered entirely unconscious and usually results a in hastened death. When palliative or terminal sedation has become the preferred plan of care, the benefit of relief must be considered against the eventual outcome of death (Bhyan et al. StatPearls).

In countries such as Canada, Belgium, and the Netherlands, where euthanasia for the terminally ill is legal under strict regulation, palliative sedation is considered a quiet alternative course of action. Maintaining dignity during emotional or spiritual suffering at the end-of-life is just as important as controlling physical pain. Contrarily, the American Medical Association (AMA) and the National Hospice and Palliative Care Organization (NHPCO) believe that palliative sedation for existential distress and suffering is not a justification for palliative sedation (Darilkova 31–33).

The policy statement of NHPCO for palliative sedation is that palliative sedation is intended to "reduce suffering by the controlled induction of sedation to manage refractory symptoms in the dying patient" and "not to be used for the purpose of hastening death." It specifies that prior to such a medical intervention, practitioners must meet all three of the following criteria:

1. death is imminent - hours to days
2. symptoms must be intolerable and refractory, and no other treatments can address the symptoms
3. the plan of sedation and risks/benefits are made explicitly clear through an informed consent process with the patient or surrogate decision-maker (Hospice and Palliative Care Nurses Association 44) (Kirk and Mahon 918)

When done correctly, palliative sedation does not, nor should it, hasten death. Notably, the data is inconclusive regarding the likelihood of hastening death, and the NHPCO appears to err on the side of caution, stating that imminent death must be a criterion for its implementation.

This inability of American medical professionals and academics to agree on the death outcomes of palliative sedation, along with the fact that human euthanasia is illegal in the United States, results in a reasonable reluctance to choose palliative sedation for symptom management. Often it can and is implemented quietly, justified by the *Doctrine of Double Effect*.

This doctrine of double effect is supported by U.S. case law (Vacco v. Quill) and addresses the physician's intention. If the intention is to relieve suffering only, a physician could be justified if the result were to hasten the patient's death. If the intention were to hasten death, then it would not be permissible by law (Darilkova 33). Obtaining informed consent prior to the intervention as required. Informed consent is covered later in this dissertation as it relates to the vulnerability and autonomy of the dying patient.

Medical Aid-in-Dying (MAiD)

While there is still an ongoing debate among health care practitioners, academics, and laypersons, Medical Aid-in-Dying (MAiD) is an end-of-life medical intervention that has also gained more acceptance in the last twenty years, as thirteen states (including Washington, D.C,) have now legislated access to life-ending medications for terminally ill patients.

The choice of MAiD is one reserved for those over the age of eighteen, having a terminal prognosis of six months or less, and being of sound mental capacity. It involves the self-ingestion of a legally prescribed medication cocktail that will peacefully end life in a matter of hours. Furthermore, while each state that adopts this end-of-life option differs slightly, there is a requirement of two physician consultations and a waiting period. Further details by state can be found here: https://compassionandchoices.org/

To complicate matters, many terminal patients are already enrolled in hospice when they choose to take part in this option to alleviate unnecessary physical and emotional suffering. What has been an unfortunate barrier for these patients, as well as a frustration for hospice nurses, is that many hospices and physicians have policies that preclude active participation by hospice staff in MAiD and often fail to disclose these policies in advance. Hospices may either refuse admission if a patient has already chosen MAiD, or they are requested to rescind their hospice benefit (Philips et al. 2-3). This can result in delayed end-of-life care, which is critical to both physical and emotional comfort (Gilbert 1). The National Hospice and Palliative Care Organization (NHPCO) policy on MAiD also remains neutral while advocating for patient education and clinical nursing knowledge on end-of-life options (Hospice and Palliative Nurses Association 2).

Practitioner opinions and personal ethical issues have also been linked to a delay in offering MAiD to terminal patients, causing patients to die prior to the end of the waiting period required to access this option. Offering MAiD is usually discussed as a last resort, rather than an option among others, for the patient and family to decide collectively in a timely manner (Seller et al. 107-108). In the context of Foucault's medical gaze, it would appear that physicians and medical organizations are allowing their biases to take priority over patient needs and right to direct their own life story.

Toward a Bio-Relational Model of Death Care

It would serve patients well for clinicians to acknowledge the complexity and nuanced relationship between objective medical knowledge and the subjective experiences of patients, particularly those nearing the end of life. These are not mutually exclusive and rely on each other for the holistic care of an individual. Because we are more likely to die from chronic disease, medical interventions are necessary at the end of life to manage the related symptoms as the disease progresses. While the overall medicalization of death is to view death solely through a biomedical lens instead of through the lens of relational care, medicine and relational care can and should co-exist in end-of-life care. The term *bio-relational* end-of-life care may be more accurate to describe the necessity of medical interventions for symptom management (not prolongation of the inevitable), alongside the critical need for relationality to address the existential aspects of death care.

Martin Buber's philosophy offers a critical lens for understanding why relational care is at the heart of ethical end-of-life care. In his I–Thou framework, an authentic relationship develops when two people meet and recognize each other as whole and unique beings. The alternative, the I–It relation, treats the other as an object to be managed or even used, reflecting the biomedical gaze of Foucault. In a bio-relational model, the philosophy is to retain the I–Thou encounter within the systems that incentivize the I–It interactions, knowing that there is a place for symptom management along with other non-clinical forms of ethical care.

What is the significance of a new bio-relational death care model? Death itself is not a pathology; disease is. A bio-relational approach to the dying process would be one that can separate the pathology from the phenomenon. Pathology is the cause of death. Moreover, while dying is undoubtedly a physical or biological process, the existential work involved for the individual cannot be overstated. Relational care demands connection to another to ensure acceptance of mortality and dignity. Death is not a disease, and it certainly is not a diagnosis. The process of dying can cause *dis-ease*; the attention and care to this dis-ease demands the attention from all medical practitioners at the very onset of any diagnosis having a terminal prognosis, especially those of a chronic nature.

Viewed through the contributions of Carol Gilligan and Joan Tronto, a bio-relational model at end of life is an appropriate theory to approach both the medical and relational dimensions of dying. Both theorists emphasize empathy, relationality, and the complexity of the human condition. They understood how easily the vulnerable can be silenced and marginalized under any form of authority, in this case medical authority.

Conclusion

Michel Foucault's concept of the medical gaze offers a critical perspective on the history of medicine and its continued tendency to objectify and strip meaning, and thus dignity, from patients, reinforcing power structures within the health care system. Apophatic inquiry helps restore meaning through reflection and contemplation. I view medicalization as a clear and alarming example of how the power of knowledge can be misused. The American medical education system falls short in teaching humility and communication skills around death, resulting in ignorance and dishonesty about prognosis and how to proceed with care in a relational manner. This is a clear contributor to moral distress for hospice nurses as they watch dignity being taken away from patients.

Medicine and relational care can and should co-exist. A bio-relational care model in the context of end of life is interdisciplinary, meaning it is synthesized and integrated. There is only one true authority, and that is the dying patient. Medical interventions at the end of life have a place in the caring relationship with the dying. The powers of medicine should consider being more cognizant of whether they are prolonging life or simply prolonging death. And these decisions must not happen unilaterally. There also needs to be a shift from the mindset of assisting in the "suicide" of another to one of maintaining human dignity. Why is human life only valued until human life is no longer viable? Why is death personified into some entity in and of itself, while we forget the living person who is before us?

CHAPTER 3

DIGNITY THROUGH RELATIONAL VULNERABILITY

“You matter because of who you are. You matter to the last moment of your life,
and we will do all we can, not only to help you die peacefully,
but also, to live until you die.”

-Dame Cicely Saunders

Introduction

Dignity thrives in spaces of relational care. To stand with the dying in their vulnerability is to affirm that their worth lies in their being. If the medical war on dying leads to diminished dignity through silencing, then relational vulnerability seeks to strengthen it through allowing for voice.

At its surface, the concept of vulnerability would seem to have a common meaning and understanding. On the contrary, it is a rich and complex human experience. All knowledge of being vulnerable implicitly and explicitly implies a potential threat of injury with a protective response. In the context of the dying person, they are in a state of relational vulnerability that is not a state to be eliminated, but identified, protected, and even celebrated.

The vulnerability of the dying is especially complicated as it involves not just a physiological process, but profound ethical, existential, and relational experiences and dependency. These elements collectively shape and support the nurse's commitment to the preservation of human dignity of the dying. American health care institutions often fail to see the dying person as a whole and still relational and uniquely vulnerable being.

Literature Review

Historical and Cultural Constructions of Death

For centuries society has prescribed or dictated how to die and how to mourn. There was no ambiguity on how to live with death as a part of life. Death was societal and culturally constructed, as it is today. The customary practice of 18th and early 19th-century America was not only to comfort the dying in their homes but to care for the body physically after death by bathing and dressing. Often, loved ones would place flowers or other keepsakes around the body to soften the experience as visitors entered the homes to pay respect. There were no funeral parlors and few, if any, formal cemeteries. These were rural communities where the dead were buried on private property.

The invention of the daguerreotype in 1839 enabled middle-class families to capture death photographically. Bodies were often posed as if alive, either alone or with family members. Death was common due to disease, especially in children, and this new craft was valuable in capturing the final image of a loved one and the memory of a life well-lived, no matter how short. Death relics soon replaced religious artifacts in a more secular time, such as mourning jewelry, locks of braided hair, cabinet photos, personal belongings, and even death narratives. All were a way to remember, honor, and adjust to the loss of the physical body (Lutz 129).

Since the early 20th century, death has been increasingly hidden from view in American society, both in imagery and everyday conversation. In its place, a widespread societal death anxiety has taken root. Psychologists describe death anxiety as a universal and multi-dimensional fear that stems from our awareness of mortality. And although death is a universal human experience, it has come to be associated primarily with fear and other negative emotions.

In response, individuals often adopt defense mechanisms, most notably denial, to avoid or suppress the discomfort that thoughts of death provoke. Death denial has been considered central to the development of psychological theory and patients seeking help with this discomfort should be supported in facing death to allow them "the creative drive to construct life" (Vance 415-28). The cultural tendency toward death denial and avoidance can have profound consequences for those facing terminal illness, making it more difficult for patients to confront their prognosis, engage in end-of-life planning, or find meaning in their final days (Becker 2-4) (Kübler-Ross 9-11).

The cultural avoidance of death not only shapes attitudes but also directly affects the lived experience of those who are dying. The dying have an increased physical and relational dependence on others for activities of daily living, management of financial matters, and health care decision-making. As the body weakens through loss of strength, speech, and mobility, they must increasingly rely on others for basic needs. This dependency can lead to a loss of autonomy, especially when patients are no longer able to participate fully in shared decision-making. In a society that prizes independence, vulnerability is often viewed as a deficiency rather than as a natural part of the human condition.

Autonomy, Vulnerability, and the Dying Role

Western ideals of autonomy may intensify the suffering of dying individuals, who risk being silenced or overlooked at a time when being seen, heard, and honored is most crucial

(Angel and Vatne 1431). To engage in relational vulnerability is to recognize the mutual and ethical significance of caring and being *cared-for*. When patients feel seen and heard by those who care for them, this connection can restore a sense of dignity and personhood that the dying process often threatens to take away.

Recognizing the demanding nature of successful caring relationships and the vulnerability required for ethical care is central to safeguarding dignity at the end of life. For care to be truly ethical and relational, the nurse must also be willing to enter a space of vulnerability to avoid becoming a detached professional. For the hospice nurse, this relational openness and authenticity demand a level of presence that is rarely acknowledged, if not discouraged, in institutional settings. The very compassion that patients depend on can turn into moral distress when systemic pressures make it challenging to respond in ethical ways.

When both the patient and the hospice nurse are allowed to show up as they truly are, the relationship shifts from one of power over to power with (Daniel 191-92). There ceases to be the customary hierarchical exchange common in medicalized death care today. To be human is to be vulnerable, and vulnerability allows for authenticity, to be who we are. All nurses risk harm to another when demonstrating any clinical distance in the name of professional boundaries. Denying vulnerability and failing to recognize themselves in others can lead the nurse to dehumanize the patient (Angel and Vatne 1429). This is what Buber calls the I-It - an objectifying relationship where Thou is treated as a thing or concept, becoming It and no longer a person.

It is common for a patient with a terminal prognosis to outlive the timeline to death as predicted by their physician. While it could be assumed that living longer would be preferential to the patient, this space between prognosis and death is where a profound, once-in-a-lifetime transition from the familiar "sick role" to the less socially defined and too often unspoken "dying role" takes place. This ambiguous dying role lacks institutional recognition and a clear social construct, thus often forcing the dying patient to move back into the sick role, where institutional resources and attention are more readily available to serve them.

Relational Care and The Dying Role

As time moves forward, the focus eventually shifts more consistently to end-of-life tasks such as handing over of practical responsibilities. This should allow for the more important emotional work involved in accepting and defining for themselves what this final role means. Here, the presence of the hospice nurse becomes critical, not just for physical symptom management, but for bearing witness and helping patients navigate the ambiguity of the dying role. Hospice is a valuable contributor to the social construct of what the dying role is and could be through relational caring, including coming to terms with the existential tasks of dying, such as meaning-making and saying goodbye (Parker-Oliver 494-95).

Many may resist acceptance of the dying role, often losing valuable opportunities to connect relationally and socially with others who may have assisted in providing some form of closure or peace (Lowrie et al. 601-6). For the dying to achieve some degree of peace at the end, communication, trust, and the ability to share fears and concerns with others must occur (Block 752). Existential death anxiety emerges when individuals are faced with questions about the meaning and purpose of their lives, particularly in light of the inevitability of death (Pandya and Kathuria 5).

Hope for a cure gradually gives way to a more spiritual and relational form of hope, one that centers on comfort, meaning, and living life to the fullest for whatever time remains. During this critical time of transition, the hospice nurse plays a vital role as both caregiver and family. The hospice nurse becomes a guide, helping patients define and pursue their sense of quality of life in the face of death while also maintaining their dignity (Broadhurst and Harrington 19).

Institutional Barriers and Medicalized Death

Dying patients are also vulnerable to systemic and institutional forces that often prioritize efficiency, control, and prolongation of life over dignity and relational care. Medicine has three principal tasks: 1) to understand how particular symptoms, syndromes, or diseases arise either in individuals or among the population, 2) to recognize ways to shorten or cure the disease, and 3) to promote living conditions in human populations that eliminate or prevent existing or future disease (Mechanic 11). Thus, medicine and traditional medical institutions are designed to deal with those who are sick and not those who are dying. Physicians are more concerned with the bio-ethical issues facing patients than the ethics of relational care (Akdeniz et al. 2).

These institutions, designed to treat and cure, can ironically amplify the vulnerability of the dying by removing them from the care and resources necessary to ensure safety, autonomy, and dignity; namely, hospices and hospice professionals. The more someone is treated in order to be kept alive, the "less alive a person is allowed to be" (Parker-Oliver 498). Even palliative care departments, though well-intentioned, can inadvertently reinforce I-It relationships by focusing on symptom management over relational presence. The gap between what palliative care can logistically offer and what the dying need continues to grow (Dellinger et al. 2).

Furthermore, although medical advancements have extended life expectancy, they have also contributed to a culture of death denial in which dying is increasingly managed within the institutional setting of a hospital. For patients with terminal illnesses receiving palliative care, much of their final days are spent being clinically *cared-about* instead of relationally *cared-for*. In this objectifying system, patients are reduced to I-It interactions, where their relational vulnerability is too often overlooked.

While some progress has been made, such as a drop in hospital deaths among cancer patients from 36.6% in 1999 to 24.6% in 2015, other data suggest that for a broader group of terminal patients, hospital death remains common, especially in the Intensive Care Unit (Teno et al. 269-70).

Drew Leder writes of living a death-enhanced life, where we become more present in our world as our time is finite. He argues we must face death as individuals in relation to others, and institutional health care should cease to reinforce death anxiety by medicalizing the process. Instead, it should assist society in accepting death and dying through a lens of relational vulnerability. Health care should no longer treat death as the final diagnosis (Leder “The Healing Body” 139).

Conclusion

Just as the dying person is uniquely vulnerable, so too is the hospice nurse in all their own vulnerability. In relational models of care, vulnerability is a shared human condition that shapes the ethical space between the caring and the *cared-for*. Hospice nurses do not merely witness the suffering of the dying, they often bond with the experience itself. This closeness can certainly create the potential for moral purpose, but also moral injury, particularly when the care hospice nurses are committed to giving becomes compromised by institutional constraints or accusations of having crossed professional boundaries.

In this space of vulnerability, dignity is revealed through the presence of another who bears witness. Relational vulnerability transforms what medicine often interprets as weakness into the deepest expression of human strength, our ability to depend, to trust, and to love each other. It reclaims dying as a profoundly ethical and communal experience, where both the hospice nurse and the dying encounter their mutual need to be seen as whole and worthy beings.

Dignity at the end of life is not found in denying weakness but in entering it with another. When hospice nurses and patients meet in mutual vulnerability, the human being is restored as a Thou rather than reduced to an It. Presence alone is not enough. The next step in preserving dignity is ensuring that the dying are not only seen, but also heard. And that their autonomous voices are allowed to shape the story of their dying. As this chapter has shown, such dignity can only flourish when vulnerability is honored rather than suppressed; when care resists the institutional impulse to control or conceal death.

The next chapter turns to a related question of how this relational understanding of vulnerability can deepen our conception of autonomy. To explore this, I move to relational autonomy*,* autonomy that is not the freedom from others, but the freedom found *through and with* others.

CHAPTER 4

THE DIGNITY OF RELATIONAL AUTONOMY

"True autonomy is found within relationships
where our decisions are made with and supported by others."
— Jonathan Herring, *Law and the Relational Self*

Introduction

If relational vulnerability shows us that dignity is preserved through presence, it is relational autonomy that demonstrates how dignity is preserved through voice. Relational autonomy is not the freedom of individual choice, but the freedom of shared decision-making. To honor patient dignity is to protect both their vulnerability and their agency, affirming that even in dependence they remain authors of their life's story.

The concept of autonomy is steeped in historical philosophical thought. It is important to distinguish between two types of autonomy, individualistic and relational. The more commonly understood is the individualistic autonomy of Immanuel Kant (1724-1804) and John Stuart Mill (1806–1873). Here, the individual is seen as an independent and self-determining agent who makes choices free from external interference. This form of autonomy emphasizes independence, rationality, and freedom from outside influence. For Mill, this freedom forms the basis for personal liberty.

As will be studied in a forthcoming chapter, this view of autonomy is the foundation for what is known in health care as "informed consent," the individual's right to make decisions even when others may disagree. This concept of autonomy focuses on self-sufficiency and overlooks the interdependence of persons through mutual vulnerability and cultural or social constructs of what shape us into who we are.

Martin Buber reminds us that the human being does not exist as an isolated “I,” but only in relation as I–Thou or I–It. When autonomy is seen as independence from others, it risks moving into the I–It, which is a relationship that objectifies patients and silences their voice. Relational autonomy, by contrast, is autonomy within the I–Thou. Here, decisions emerge through dialogue. To preserve dignity is not only to protect choice, but to ensure that choice develops through and in relationship with others.

Relational autonomy emphasizes decision-making in the context of others. In health care, these influences are impactful as they enable and support the patient to ensure dignity and choice. In death care, autonomy is less about independence and more about presence and ensuring an environment that allows for the voice of the patient during this lived experience. Relational autonomy ideally demonstrates the complexity of relational care and shared decision-making, especially at the end of life when circumstances are often nuanced, but critical.

This chapter will demonstrate how usurping autonomy exerts control and undermines patient dignity and how relational autonomy helps preserve patient control, supporting a dignified dying process. Moral distress in hospice nurses often emerges when the autonomy of the dying is threatened. Hospice nurses often instinctively recognize what constitutes ethically appropriate, patient-centered care that can be hindered by systemic and hierarchical barriers. It is this instinct that separates true nursing care from clinical tasks and procedures. Loss of relational autonomy thus not only compromises the nurse's ability to provide ethical care, but also threatens the dignity and voice of the patients they serve.

Literature Review

From Self-Law to Shared Decision-making

Autonomy means "self-law" and is an ancient concept with roots in Greek politics. Attention was originally placed on the independence of city-states with no attached philosophical meaning (Beachamp and Childress 99). Over the centuries autonomy has been philosophically studied in relation to individual or personal autonomy in the areas of education, health care, and legal freedoms. As discussed, Kant and Mill conceptualized autonomy in individualistic terms. It was Jean-Jacques Rousseau (1712–1778) who offered an early vision of what is understood today as *relational autonomy* with its modern foundations in feminist care ethics.

Rousseau's *The Social Contract* (1762), argues that true freedom is not the ability to follow one's private will but to participate in the "general will." He questions the ability to truly act freely while also living socially with others (Williams 100). Similarly, Martin Buber's dialogical philosophy stresses how human existence is inherently relational and that the self can only fully develop through relationships with others (in the I-Thou). Both Rousseau and Buber challenge individualistic autonomy by highlighting that through relationships and dialogical presence is where we find dignity and freedom.

Autonomy in Biomedical Ethics

Autonomy oftentimes remains a concept that is steeped in vagueness. It was not until Beachamp and Childress in the 1970's that it became a mainstay as one of the four principles in biomedical ethics - the other three being beneficence, non-maleficence, and justice. In *Principles of Biomedical Ethics* (1979) Beauchamp and Childress define autonomy primarily as self-rule that must be free from controlling influences. They emphasize the capacity for independent choice, rational deliberation, and freedom from coercion.

This has been the framework of biomedical ethics ever since, particularly in establishing laws and practices around informed consent (Beachamp and Childress 104). What this descriptive and non-evaluative bioethical model of autonomy does not do is demonstrate the value in the relational aspects of autonomy that we now see in feminist care ethics. Critics contend that they over-emphasize independence and understate interdependence. (Saad 133-35).

Childress responded to critics of their narrow, individualist approach to autonomy by acknowledging that individuals are social beings formed through relationships. He stops short of endorsing the relational autonomy of feminist care ethics. Childress sees some relationships as potential threats to the ability to act autonomously when some of these relationships can cause undue influence or coercion on the individual. Autonomy is something to be *protected* from relationships (Childress and Quante 141-44). Contrarily, families should be regarded as partners in the patient's decision-making rather than treated merely as third parties (van Nistelrooij 3).

Modern biomedical ethics has introduced the legal concepts of *capacity* and *competency* into discussions of autonomy and informed consent. *Capacity* refers to a patient's ability to understand and communicate decisions regarding their health care, including an awareness of potential risks and benefits. *Competency*, by contrast, is a legal determination made by a court regarding an individual's ability to participate in legal proceedings, such as entering contracts or providing informed consent. When a patient is deemed legally incompetent, a legally recognized authority is appointed to act on their behalf (Vignarajah e673). Importantly, this does not prevent a competent individual from designating a health care proxy or surrogate decision-maker in advance, should they later lose the capacity to make informed decisions.

A Shift to the Relational

While these legal designations provide patients with important safeguards against coercion and exploitation, they also demonstrate a limited view of autonomy by being understood solely through an individualistic, rights-based lens. Here biomedical ethics overlooks the relational realities of quality patient care and how ethical choices are made. The bilateral covenant between physician and patient no longer adequately reflects the realities of twenty-first-century health care (Stirrat and Gill 127).

The vulnerability of the dying patient is both unique and profound, as discussed in the prior chapter. From a bioethical perspective, the level of vulnerability can be considered an influence on the patient’s capacity for autonomy. Patient autonomy at the end of life is not an isolated exercise of individual choice. Instead, decisions emerge through relationships of trust, vulnerability, and dignity, especially between the patient and their hospice nurse. It is in this context that the concept of relational autonomy offers more humanizing, and thus ethical care.

Dependence on others does not necessarily undermine autonomy, but may instead "shape it in constructive ways" (Morberg Jämterud 954). The vulnerability of the dying is not merely a condition to be managed, but the very space in which the work of dying can develop. Hospice and palliative care seek to honor this space by addressing physical, spiritual, and psychological suffering in ways that recognize the patient as inseparable from family and relational dynamics.

This "relational communication" by clinicians is something that supports patient autonomy. The ethical clinician can provide a nuanced explanation of health care implications that can serve to *protect* from other communication that can be deemed coercive or misleading. Clinicians can help the patient recognize the potentially oppressive aspects of health care and encourage them to "form, maintain or re-establish self-identities" (Entwistle et al. 744).

Paternalism's Relational Challenge

Paternalism was once viewed as both natural and necessary. Patients entrusted their lives to physicians who assumed the role of trusted guardians. The physician's responsibility was to cure or comfort, with no expectation of patient autonomy. Within the last several decades, the assertion of the right to autonomy has caused problems with the general theory of paternalism in medicine. The idea of beneficence (to do good) from a bioethical standpoint supports paternalistic behavior by physicians. To deny the relationality of ethical care and thus putting patient autonomy at risk can be considered contrary to beneficence (Beachamp and Childress 207-9).

Proponents of medical paternalism often assume that patients are incapable of making informed decisions, arguing that illness itself can compromise sound judgment. From this perspective, restricting a patient's choices, particularly to prevent self-harm, is framed as a form of respect for the individual's well-being. Critics have characterized paternalistic practices as a "superiority problem," rooted in the physician's sense of authority and often resulting in the treatment of patients as if they were children (Fleisje

541). Making decisions on behalf of oneself is also considered “conducive” to one’s own well-being, not just a legal right (DeGrazia and Millum 115).

A review in 2013 of 44 studies on patient-reported experiences of shared decision-making found that barriers and facilitators centered around both institutional structures and clinical encounters with practitioners. Patients frequently lacked not only the knowledge but also the power to participate fully in decisions. Reasons ranged from time pressures of staff, continuity of care, and workflow constraints. Relational factors included communication, trust, and the power imbalance between clinicians and patients. The study concluded that knowledge alone is insufficient and that meaningful shared decision-making requires a shift in culture, structure, and relationships to support patients in exercising both agency and voice (Joseph-Williams et al. 306-8).

A gap remains between autonomy as an ethical principle and autonomy as it is practiced in clinical settings. There needs to be reconceptualization of autonomy as explicitly relational, thereby strengthening patient-centered care and ensuring greater respect for patient agency. The historical bioethical framework that privileges individualism also overlooks the relational dimensions of decision-making. By contrast, a feminist relational account of autonomy emphasizes communication and partnership, which should be regarded as vital to truly patient-centered care (Ells et al. 79–81).

Conclusion

Autonomy, which facilitates dignity, is the cornerstone to ethical health care. How a patient chooses to live their life should not be silenced when facing death. We live our bodily existence until our last breath, leaving behind a legacy of this life that will continue even if we are never to be remembered. Autonomy through dialogue and relationships with others is what will preserve dignity until the very end.

Relational autonomy is found in the space *between* self and other. It transforms choice from a solitary act of will into a dialogue of shared meaning and decision-making. Here freedom is found not in separation, but in relation. In ethical and dignified death-care the patient's voice is neither isolated nor overshadowed, but carried and protected through mutual trust, presence, and ethical listening. When autonomy becomes relational, care itself becomes almost conversational, enhanced by compassion rather than control.

Consent cannot rest on the "illusion" of perfect independence but must be rooted in trust and communicative openness (O'Neill 35). In this sense, informed consent is not merely a procedural safeguard but the ethical practice through which autonomy is honored as relational and deeply tied to dignity at the end of life.

The following chapter demonstrates how relational ethics deepens the meaning of autonomy through informed consent, arguing that true consent is not obtained through a signature on a form, but through shared decision-making that honors dignity and relational care.

CHAPTER 5

THE MORAL POWER OF INFORMED CONSENT

"True consent arises only when vulnerability is met with attentiveness,
and dignity is safeguarded in the act of listening."

Adapted from Edmund D. Pellegrino and David C. Thomasma,
For the Patient's Good: The Restoration of Beneficence in Health Care*, Oxford UP, 1988.*

Introduction

Autonomy offers the ethical grounding for respecting individuals as self-determining agents. It remains incomplete until it is supported in practice. The most visible expression of autonomy in health care is informed consent, where the principles of respect, dignity, and choice are brought into the reality of the clinical encounter. Informed consent is not merely a legal safeguard or a signature on a form. It is a moral dialogue that requires relational presence, attentiveness, and trust.

Just as autonomy must be understood relationally rather than individualistically, informed consent must also be approached as a shared ethical process that honors vulnerability, safeguards dignity, and resists reducing the patient to an object of medical intervention. It is within this dialogical space that the moral power of informed consent emerges. As Nora O'Neill argues, respect for persons is not demonstrated merely by securing explicit agreement to a particular decision. Rather, it lies in treating others as agents capable of giving or refusing consent. In this sense, what matters most is sustaining the *possibility* of consent itself. When biomedical ethics reduces autonomy to procedural documentation, asking only whether the patient signed a form, it risks overlooking the deeper moral question of whether the encounter truly recognizes the patient as a person within a relationship (O’Neill 259).

Literature Review

Brief History of Informed Consent

The legal foundation for informed consent and patient rights began in the early 20th-century U.S. court case of Mohr v. Williams (1905), Pratt v. Davis (1905), Rolater v. Strain (1913), and Schloendorff v. Society of New York Hospital (1914). All of which established the principle of patient autonomy and the right to control one’s own body. The term “informed consent” itself first appeared in Salgo v. Leland Stanford Jr. University (1957), which emphasized the physician’s duty to disclose all possible procedural risks (Bazzano et al. 81-83). (Figure 3).

Legal & Historical Foundations of Informed Consent

- Mohr v. Williams, 95 Minn. 261; 104 N.W. 12 (1905). Early recognition of patient’s right to bodily integrity.
- Pratt v. Davis, 224 Ill. 300; 79 N.E. 562 (1906). Reinforced consent for surgical procedures.
- Ro later v. Strain, 39 Okla. 572; 137 P. 96 (1913). Extended doctrine of battery for lack of consent.
- Schloendorff v. Society of New York Hospital, 211 N.Y. 125; 105 N.E. 92 (1914). Famous line: “Every human being of adult years and sound mind has a right to determine what shall be done with his own body.”
- Salgo v. Leland Stanford Jr. University Board of Trustees, 154 Cal. App. 2d 560; 317 P.2d 170 (1957). First use of the phrase “informed consent.”
- Canterbury v. Spence, 464 F.2d 772 (D.C. Cir. 1972). Established the “reasonable patient” standard for disclosure.

FIGURE 3

In research ethics, the Nuremberg Code of 1947 marked the first explicit international standard requiring voluntary consent, followed by the Declaration of Helsinki in1964 and the Belmont Report of 1979**.** The Belmont Report highlighted three elements of informed consent: information, comprehension, and voluntariness, with particular attention to how information is conveyed, not just what is disclosed (Saad 131-33).

It was not until Beauchamp and Childress published their seminal work *Principles of Biomedical ethics* (1979) that informed consent found its footing in modern biomedical ethics. As discussed in the previous chapter, informed consent, like autonomy, was now approached descriptively instead of evaluatively, with scholarly critics arguing the loss of connection to trust and dignity by focusing more on the legalities of process. Understandably, it would seem that informed consent in modern biomedical ethics has sought to protect against paternalism in health care. What has been lost is the person in relation behind the given consent to treat.

O'Neill would further argue that the legalities of informed consent have ignored the necessity for shared decision-making due to the inherent vulnerabilities of the sick (Parsons 249). In focusing narrowly on documentation and liability, legal frameworks risk treating patients as isolated individuals capable of fully autonomous choice, overlooking the relational realities of illness. Patients often rely on caregivers, family, and clinicians not merely to deliver options but to help interpret them, to provide context, and to share in decision-making. By neglecting this shared dimension, informed consent procedures can inadvertently reduce the patient to a passive signatory rather than an active participant in their own care.

Informed Consent and Personhood

Through the continued lens of Martin Buber, genuine ethical encounters arise only in the I–Thou relation, where the other is engaged as a whole being rather than reduced to an object to be controlled. Traditional informed consent, grounded in procedure and documentation, risks falling into an I–It encounter, where the patient's signature becomes more important than their voice. By contrast, Hagopian (2024) calls for empowered consent that is relational, continuous, and rooted in dignity to ensure I–Thou presence within the clinical encounter. It reframes consent as an act of recognition and dialogue, grounded in authentic shared decision-making. In this sense, empowered consent is not only an ethical safeguard but also a profoundly relational practice, one that preserves dignity at the end of life by ensuring the patient remains a Thou and never merely an It.

As discussed, the current biomedical model provides legal definitions of capacity and competency that primarily serve institutional and professional protections. While these legal frameworks are necessary, ethical care requires more than procedural compliance; it calls for dialogue, attentiveness, and relational responsiveness. The vulnerability inherent in serious illness makes shared decision-making central to ethical care. Confronting the physical and existential realities of dying often exposes individuals to profound distress, limiting their ability to exercise the ideal of independent self-rule.

Consider, for instance, when patients lose decisional capacity. Their families are uniquely positioned to carry forward their values and wishes, not by guessing in isolation, but by drawing upon shared stories and ongoing bonds of care with each other. Here, patient and family together shape choices, even when one voice falls silent. This view challenges the legalistic insistence on "clear and convincing evidence" of prior wishes, which too often leaves patients "imprisoned" in burdensome treatments (Kuczewski 29) and goes to the very nature of O'Neill's argument for allowing the *possibility* of consent though dialogue.

Kuczewski writes of reframing this current doctrine of “substituted judgment” (Kuczewski 29) not as a failure of autonomy but as its extension through relationship. In this sense, substituted judgment is a form of shared decision-making, affirming the relational dignity of the patient. It recognizes the person and their preferences as discovered through past conversations with loved-ones. For end-of-life decisions, such shared decision-making safeguards dignity by resisting the reduction of the patient to a mere object of medical technology (I-It), honoring instead the personal narrative that gives life meaning even during the dying process.

The Practice Realities of Informed Consent

Despite its prominence in biomedical ethics, the principle of informed consent can create deep tensions when carried into practice, especially at the end-of-life care. On the one hand, it is intended as a safeguard for patient autonomy. On the other, its legal requirement often reduces it to a procedural formality. Clinicians may be compelled to prioritize documentation over dialogue, ensuring liability coverage rather than fostering genuine understanding. What was meant to protect the patient’s autonomy risks undermining it by treating the patient as a mere signature.

The American Medical Association Code of Medical Ethics (Informed Consent) acknowledges the role of surrogates when patients lack decision-making capacity. Its policy on informed consent remains framed almost exclusively as a conversation between a physician and patient. This model overlooks the relational aspects in which most decisions are actually made, especially in the context of serious illness and end-of-life care. By limiting “others” to legally appointed surrogates or institutional actors with access to health data, the AMA neglects the ethical significance of family, nurses, and caregivers who often share in both the burden and the meaning of decision-making. The effect is a consent framework that secures legality but fails to capture the dialogical reality of care.

From a Buberian perspective, such a model reduces the patient to an "It," isolating them within a procedural exchange rather than acknowledging the Thou sustained through webs of trust, vulnerability, and shared presence. In this way, the AMA's policy perpetuates the very individualism that relational consent seeks to overcome, silencing the voices most attuned to safeguarding patient dignity.

This gap between philosophical accounts and everyday activities involving medical consent further complicates its practice in health care, as recent studies reveal that what the public regards as 'valid consent' often differs from the ethical standards necessary to safeguard patient dignity. The findings of Demaree-Cotton and Sommers highlight a significant tension between "folk" intuitions about consent and the ethical demands of autonomy in practice. Their studies show that ordinary people often regard consent as valid so long as the individual possesses the *capacity* for autonomous decision-making, even if they fail to exercise it rationally (Demaree-Cotton and Sommers 105065).

Such a view reducing the relational and dialogical nature of autonomy to a condition of mental competence rather than an ongoing practice of recognition and care overlooks the mutual responsibilities, vulnerabilities, and bonds of trust that make autonomy meaningful at the end of life. In the context of end-of-life care, this simplified concept of valid consent ignores the ways vulnerability undermines a patient's ability to exercise their autonomy without relational support.

Conclusion

True autonomy is not merely possessed but lived through dialogue. Thus, while the folk concept of consent works well within legal systems and institutions, it fails to safeguard dignity or address the moral distress of clinicians who witness this gap between procedural consent and shared decision-making.

For hospice nurses, this tension is particularly acute. Shared decision-making requires time, presence, and the willingness to enter into relational dialogue. Institutional pressures, limited staffing, risk-averse protocols, and the demand for efficiency often force conversations into quick, transactional exchanges. The tension grows if the dying patient is also struggling with symptom management. This compounds their vulnerability.

As O’Neill emphasizes, the sick cannot be presumed to act as fully independent agents detached from their circumstances. Their autonomy is sustained through relationships of trust, care, and presence. Legal frameworks of consent rarely accommodate this relational dimension, ignoring the need for shared decision-making and potentially ignoring patient dignity.

In addition, paternalism remains a challenge in hospice and palliative settings. While informed consent is often presented as the safeguard against paternalistic practices, paternalism persists in both overt and subtle forms. Palliative care decisions frequently invoke a “palliative paternalism” when clinicians, facing the urgency of declining health, assume authority over choices that might otherwise be shared with patients (Roeland 253).

Similarly, the notion of “selective paternalism,” describes how clinicians may consciously or unconsciously filter or frame treatment options when shared decision-making is perceived to have failed (Drolet 582). Lynøe and colleagues go further, exposing the phenomenon of “disguised paternalism,” in which patients are offered choices that appear autonomous but are in fact heavily shaped by professional framing (Lynøe et al. 2021).

Nurses who recognize the patient as a Thou are compelled by a medicalized death care system to treat them as an “It,” an object within a consent process rather than a whole person in relation. Here Buber’s dialogical philosophy exposes the ethical dilemma: when the encounter is reduced to procedure, the possibility of dignity is diminished. These competing forces, procedural/legal versus relational, constitute a large gap in informed consent in practice.

Medicalization and paternalism in death care are ongoing practices embedded in the very structures designed to protect patient autonomy. For hospice nurses, this tension magnifies moral distress, as they are often asked to safeguard patient dignity in systems that continue to silence or attempt to shape patient voices to their meet the goals of others.

PART III: UNKNOWING

APOPHATIC INQUIRY I:

BEARING WITNESS TO MORAL COST

The Inner Space

During Althea’s final days, I witnessed the collapse of a relationship of care into that of a procedure. What transformed left me wounded. Althea’s physician’s decision to administer a continuous morphine IV silenced all dialogue. Her expressed desire to return home would be her last attempt to control her dignity as a patient and my moral grounding as her nurse. More than an ethical dilemma arose when the physician spoke the words, "Let her fade away."

The relational care I was providing began to unravel as I felt her disappear and *fade* into the world of medicalized death care. I sat at the nurses’ station talking into the phone to a man who was not hearing what I was saying. My voice was also silenced. I could feel all eyes on me as I hung up the phone and dialed my hospice director. Surely she would be able to intervene and provide me some guidance.

Once again, I was dismissed as my director responded to my explanation of the situation with, “Oh no, not another one.” She would offer no solution or guidance. How often has this happened and why is nothing being done about it? The eyes of others kept their stare. I felt heat rise around me while I lost all sense of hearing. As I have come to understand through the lens of Martin Buber, I was witnessing the evolution of a person into an object. Althea was in fact fading – fading from being met as Thou to being treated as It.

Upon returning from my family vacation I was further betrayed by my leadership team when they accompanied me to my patient visits in what felt to me to be a further effort to intimidate and silence me. I was told they wanted to make sure I did not take any of my “anger issues” into patient homes. At one point before entering a patient’s apartment building I broke down crying. The manager looked into my eyes as she comforted me. I could feel that she knew what the agenda was, all the while being a part of the culture of silence.

What is it about the nature of a caring relationship between a nurse and their dying patient that can put a nurse at moral risk? I have come to realize how my relationships with my hospice patients, while still professional, have also been highly personal. As time moves closer to the end of life, something mysterious and wondrous occurs. I have laid witness to so many transformations from bodily existence to cosmic unity. One can only imagine what the dying are experiencing.

Nursing school teaches the importance of maintaining healthy boundaries, emphasizing that feeling or showing sympathy is not considered professional. And while it is acceptable to empathize with a patient, personalization is discouraged. Sympathy and connection demonstrates concern for another. It is no less therapeutic, nor is it inappropriate in nursing care. Concern may be the primary requirement for the beginnings of a nurse-patient relationship. Feeling concern creates a commitment and, in turn, the acts involved in caring. Empathy is the added benefit of knowing and understanding another. Care ethics literature consistently challenges such rigid distinctions between the personal and professional, and the public and private, demonstrating how care practices routinely crisscross these boundaries. Tronto, for example, argues that confining care to the private sphere conceals its moral and political significance, particularly in professional caregiving contexts where relational, emotional, and institutional responsibilities meet (Tronto “Moral” 1-3). This tenson can be seen as a key contributor to nurse moral distress (Hansen et al. “Ethical” 1927-28).

The Aesthetic Space

A unique bond encapsulates those at the bedside of the dying. Many are partners in a profound relational process that has a once-in-a-lifetime outcome. Intuitively I begin to know my dying patient, as there is something beyond the senses that is occurring before me. I understand what is said; more importantly what is not said. This ability comes from deep inside like a bubble filled with so much to give; knowledge, experience, love. My care is an inherent ethical obligation that I gladly undertake, where I find peace in protecting the vulnerable during their final journey.

The origin of this knowability is mysterious and can come at a cost. Buber called this the *zwischenmenschliche*, the “between,” the living relational space where two beings meet in truth (Buber 181). In this space, knowing is not derived from clinical data alone but from mutual presence, where both nurse and patient are transformed by the encounter (Evans “Wonder” 97).

Althea’s silencing was deafening to my ears and my heart. What I encountered was a spiritual unravelling, where ethical knowing met its limit. I paid the cost of caring when ethics and power were no longer in balance. The moral distress I experienced as a result of Althea’s silencing was an ongoing assault on my soul. I felt angry, sad, and guilty as I punched at this situation with all my might. I lived years with an ever-present dark cloud of injustice in the back of my mind. Caring for the dying is inherently sad. But that is okay. Sadness comes from the loss of a meaningful and transformative relationship. Sadness can coexist with the peace that comes from unknowing. It is the distress from disruptions in a relational commitment that is the insidious betrayer.

I too was fading away, losing my own voice. Nursing is a lonely business. I heard in nursing school that nurses are known to "eat their young," and I had certainly had the scars from my share of bite marks. What I was facing in Althea's case was a toothy animal of another kind, the goliath of a health care system.

In my practice I thrive in the symmetry and balance that manifests in relation with the dying. It is as much a spiritual act of caring as it is a medical one. This relational *between* is where I am whole, advocating for patient justice and the desire to protect and heal. Any threat to the integrity of this bridge is where moral distress can take root and grow, like the poison ivy that creeps into a well-kept garden.

"Justice" watercolor and ink. Denise Gawley 2025

The Wondrous Space

To experience a sense of wonder, one must be open to seeing without eyes and listening without ears. This case highlights the growing need for clinicians to practice relational death care. Care is more than theory. Some philosophers argue that a sense of wonder is fundamental to the possibility of ethics (Hansen et al. "Wonder*"* 22). There is a profound mystery in how humans are inherently connected and require each other's care to live fully and justly within a healthy community. Wonder awakens this awareness. It is not curiosity or sentiment, but reverence for what lies beyond understanding to help us navigate what challenges us, such as maintaining the dignity of human life as it fades away.

Buber would say that the sense of wonder and mystery (found in the *between*) is lost when the transition from Thou to It occurs. Providing ethical health care begins with acknowledging this *between* of our humanity in relation to others and understanding that our intrinsic ethical nature already influences our actions. Althea was objectified in a world of medical interventions, ceasing to be *cared-for* in an ethical manner. Perhaps this objectification weakened the intrinsic ethical nature of her physician's actions, which were not likely dubious in nature. Could he unknowingly be merely part of the system in which medical clinicians work? If only he had heard what Althea was really saying; not that she desired to return home, but she desired to return home to *die*.

Conclusion

What remains after Althea's death is not resolution but residue, a more quiet ache that refuses to leave. Her fading exposed something irreducible about care: that to accompany the dying is to be changed by them, marked by the weight of their absence.

The moral distress I carry is not a failure of professionalism but the cost of living in a system that has forgotten how to listen.

Through apophatic inquiry, I have come to understand this sorrow not as pathology but as witness. It reveals the suffering and the ethical heartbeats beneath the silence and loss. To feel the moral cost of care is to affirm that our humanity remains intact, even when the structures around us act as more of a barricade than a bridge. Love, grief, and justice are not separate tasks to come to terms with, but shared reminders that of the cost of bearing witness.

Until I faced my moral distress through apophatic inquiry, I lived with the pain of having witnessed the fading of another's dignity without the power to intervene. This is the essence of moral distress: a deep knowing that something has been violated. It is also, paradoxically, a form of self-forgiveness and grace, revealing how deeply I have been bound to those I have served. To feel the moral cost of another's fading is to remember that love itself is an ethical act to be proud of. If caring like this caused me such moral distress, it was worth it.

APOPHATIC INQUIRY II:
THE MEDICALIZED SILENCING OF THE BODY

The Inner Space

Could Althea's care in her final hours be considered a medicalization of end-of-life care, and if so what was the impact it had the nursing relationship of caring? In the silence that was Althea's fading away, I saw the true foundation of that silence; hierarchies and medicalized death care. Was what I experienced as moral distress simply caused by another's actions, or was it actually a symptom of an entire system that values and choses interventional care over relational care at the end of life?

In this space, the dying body can easily become an object with symptoms to manage, as the nurse becomes a witness restrained by policy, efficiency, and paternalism. Through apophatic inquiry once again, I turn toward what cannot be documented in a patient chart.

A child raised under the thumb of a parent who took pride in authoritative love can cause so much inner noise for that future adult. Thus, I come to nursing with a bias toward various forms of authority. I have encountered superiors who misuse their power and fail to work collaboratively in ways that foster relational care and respect for all. I even resigned a position refusing to break the law when asked to sign out a medication which another nurse administered weeks earlier.

Was Althea's physician an exception or the norm? My hospice director led me to believe this was common - a physician placing a hospice patient on continuous morphine intravenous administration. What she was really conveying to me was that another hospice patient is going to die prematurely. The question of informed consent was not even a thought at that moment. Authority can crush the relationality of care, causing a suffering that hurts without an actual physical stimulus.

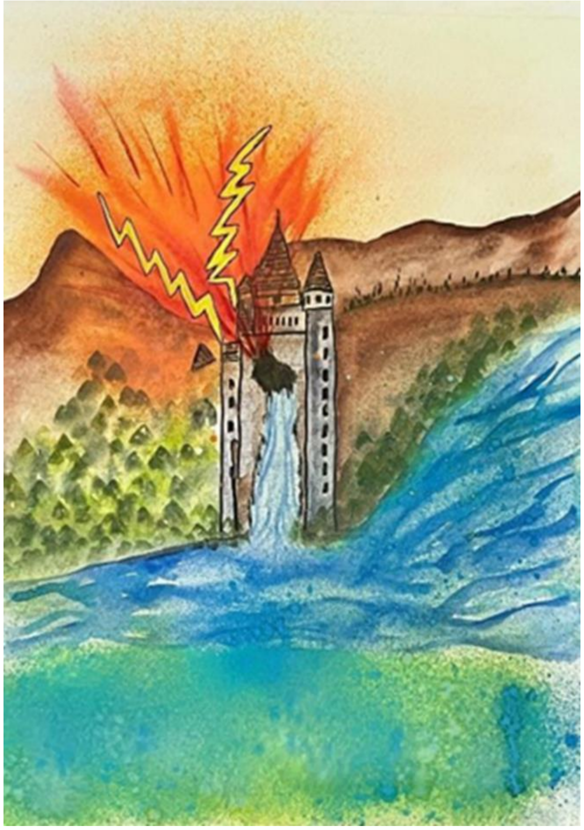
Althea and I were both proverbially robbed of our relationship with each other. It appeared that Althea and her son were also denied a moral and legal choice to decide what intervention best suited Althea's closing chapter. Althea had a full lifetime behind her, only to have it halted by an institutionalized wall that had been built over the course of her care.

The Aesthetic Space

I can still feel the hollow of grief in my chest and see my painted stone kitchen wall in front of me as I spoke with Althea's son, trying to answer his question of why his mother died so quickly. I chose my words carefully, and in that restraint anger and frustration began to get acquainted inside me. I did not tell him the full story, even if it was his story, as well. I did not think additional chapters needed to be added, and I was also unclear how to navigate such a legal issue with him. I hope he found a place where his grief could rest.

The power of the American medical establishment can appear like the walls of a fortified concrete tower, holding the damsel hospice nurse and her vulnerable dying patient hostage to the will of hierarchical and societal dictates of what constitutes a *good death*. Is a good death even definable by anyone but the dying? How utterly arrogant to think anyone could even begin to define a good death for another.

Who will take up the hammer and use it to break down these walls, block by block? What will cause a directional change from continued medicalized death care to that of a human experience assisted by, instead of dictated to? It may be as hard as causing a river to flow uphill. We have the right to script our own stories, and our last chapter should not be controlled by the publisher.



"The Fortress of Medicalization" watercolor & acrylic. Denise Gawley 2025

The Wondrous Space

We should all be able to assume that medical practitioners have an intrinsic nature to want to heal. The medical profession appears more of a reflection of a society that seeks fixes instead of the healing. For most of us, life is worth living. For many of us, dying seems to be preventable given so many options for medical interventions, no matter how futile.

And what does it mean to heal? Healing may appear as the formation of a scar on the skin, a visible sign that a wound has closed. Wounds to the soul or the psyche also leave scars, though invisible, and raise deeper questions about whether healing has truly taken place. Whatever healing may be, and whatever form the scar takes, there remains a lingering reminder of injury, even when what was broken appears whole again. Remnants of the wound persist: a residue, a sense of absence, or perhaps a promise of care that was never fully realized, as in my own case.

Althea's death could be seen as an example of medicalized end-of-life care. The American health care system lacks consistent attention to existential suffering and relational healing. It often fails to honor the dying with dignity through the prioritization of legal and hierarchical norms over human needs. Caring is not a soft skill relegated to nurses, but an obligation of society.

The physician's medical gaze, the bureaucracy of cost containment, and even well-intentioned interventions can objectify the dying person, rendering them an "It" rather than a Thou. This depersonalization not only harms patients but also inflicts moral distress on hospice nurses, who must witness the diminishment of dignity in those entrusted to their care.

Conclusion

The medicalization of death has profoundly shaped how all aspects of suffering at the end of life are interpreted and managed. Within a healthcare system designed to diagnose, intervene, and prolong biological function, dying can easily become framed as a clinical problem to be controlled rather than a human experience to be accompanied. Such an understanding invites healthcare professionals to move beyond the management of the body alone and toward a form of care that remains attentive to and in relation with the person who is dying.

Death is a natural process. It will and must happen to all living things. Seneca the Younger, a first century Roman, was a devout follower of Stoicism, a philosophy that emphasized virtue, reasoning, and living in harmony with nature. Seneca taught that death was not something to be feared. As with life, death is neither good nor bad. It just is. To die well means to live well and is certainly subjective. Society must learn to live well and accept death with courage. We should have the courage to demand from the medical profession a partnership that supports what it means to each of us to live well, so that death comes with acceptance and ease, not unnecessary medical interventions.

APOPHATIC INQUIRY III:

THE STRENGTH TO SURRENDER

The Inner Space

In what way is the dying person vulnerable and how is the nursing relationship unique from other caring relationships? To be vulnerable in the context of dying is not to be at risk of harm, but to be exposed and open to uncertainty, dependence, and deep relationality. This openness reflects the essence the Buberian I-Thou encounter, where both the nurse and patient are mutually present, acknowledging each other's full humanity.

It is through relational vulnerability that the work of assisting the dying emerges. It is a profoundly human process. I have felt this relational vulnerability without ever being able to name it. This space between me and my hospice patient is not a place of liability, but a place to make an unseen, yet profound connection.

We do not just die once. We die many little deaths as we lose all the varying elements and meaning that make us who we are. I have not cared for a more vulnerable patient than Althea. Many of my hospice patients (and their families) over the years have had such frightened looks on their faces, often living experiences that could equate to social or even medical abandonment. Friends and colleagues do not know what to say, treatments and interventions are over, and physicians pass symptom management responsibilities onto the hospice nurse. This leaves the patient alone to navigate the mysterious role of a dying person.

Although Althea died physically in her hospital room at the end of the hall (where all inpatient hospice patients seem to be placed) our relational presence with each other transcended her bodily absence, underscoring the ethical significance of mutual vulnerability. Connection such as this may be the most profound reason moral distress can find its way into the soul of a hospice nurse. We do not simply lose patients. We continue to carry them, sometimes feeling responsible to them, never fully releasing the unseen ethical presence we once held. Our caring commitment lives on in us, even if through moral injury.

The Aesthetic Space

After my leave of absence and my subsequent return to work, my request to meet as a team (including Althea's physician) was granted. I needed to know if consent was obtained and honestly wanted Althea's physician to be held accountable for saying he was going to allow her to "fade away." Naively, I envisioned an open discussion and with a final end to it all.

The conference room was a windowless box that held three other people whose eyes seemed to sear directly into me like red beams of light. It became immediately clear that this meeting was not going to proceed as I had hoped, as I soon learned that Althea's physician was being "represented" by another physician (whom I did not know) via teleconference, of all manners.

Neither the social worker nor the clergy on Althea's case spoke a single word. Between glares I sensed embarrassment in them. I regret not directly asking them to support me. Apparently to assume my fellow clinicians would do the right thing when necessary is a personal weakness. My frustration and feeling of abandonment manifested in an unfortunate, albeit authentic display of anger, vulnerability, and cursing.

The sense of loneliness was overwhelming as I made my way down the hospital hallway that filled with stark fluorescent lighting that is never conducive to a calming environment. out of the hospital that day. I was singularly trying to fight for Althea's dignity against what I viewed as the injustice of a health care machine, and no one cared about either of us. My manager was merely acting as a robotic arm attached to this machine, charged with its protection at the cost of care.

Vulnerability is not weakness, but the strength and courage to surrender to that which is overwhelming. To be relationally vulnerable provokes both fragility and strength simultaneously. In relationships, there is presence. In vulnerability, strength. Through relational vulnerability, there is a possibility for ethical care.

"The Strength to Surrender" watercolor multi-media. Denise Gawley 2025

The Wondrous Space

The relationship between hospice nurses and their patients is a space of ethical caring that will often resist closure, more so for some nurses than for others. Nurses who form deep reciprocal bonds with patients who are dying may experience a more substantial ethical presence that persists even after death. It would also seem logical that those who chose the path of nursing follow a natural path for their personalities; being open, trusting, and sympathetic to the needs of others. These qualities could also inherently place nurses at a higher risk for moral distress. Apophatic inquiry, as this dissertation examines, could be a significant tool for healing nurse moral injury.

It would be a curious examination to understand more fully how nurses and physicians care differently and experience forms of moral distress. The answer could be in the long-established identity and culture of the nursing and medical professions that influence how we care. Both experience training and education that emphasize detachment as a form of professionalism. Does this protection from vulnerability not come at a cost to ethical patient care?

Not everyone can open themselves up to this vulnerability, and thus, the natural flow of trust and ethical behavior can become clouded or even blocked. My professional relationship with Althea’s physician demanded that I trust him. I opened myself up, vulnerable to his actions, as he was the one with the power and credentials to act. I suspect he felt he was acting ethically, protected by the theory of paternalism, by allowing her to "fade away." Maybe his behavior was influenced by his own reluctance to experience vulnerability. What I am learning is that love and resilience requires me to *drop the stethoscope* and keep moving forward.

Conclusion

Hospice nurses face the tragic reality that most Americans are afraid to die. The most peaceful and death-accepting patients I have encountered in my hospice tenure have been those who formed healthy relationships with others over the course of their lives. It is in these relationships they found meaning, discovered their authentic selves, and learned how to maintain a sense of dignity at the end. For all of us, being in relationship with others requires vulnerability, which requires strength and courage. For Martin Buber, there is no isolated "I" outside of relationships. There is only I-Thou. Our entire being is based on our relationship to others. We become who we are through these encounters, not in isolation (Buber 53).

For a hospice nurse, the courage to enter I-Thou relationships with the dying allows vulnerability to become a source of strength, presence, and ethical engagement, resisting the depersonalization inherent in medicalized death. This courage to be vulnerable is scarce in a culture where death and dying have become behind-the-scenes occurrences, reinforced by an American health care system that prioritizes profits through over-treatment and false hope. In end-of-life care, relational vulnerability is not a professional liability, but a form of ethical dimension. This vulnerability facilitates authentic presence, supports the preservation of dignity, and resists the depersonalizing tendencies of medicalized death.

American culture often equates vulnerability with weakness. On the contrary, the dying patient's vulnerability is uniquely human, expected, and even beautiful, as the hope for a cure gives way to the sense of having lived a meaningful life. Suffering is "a complex amalgam of physical symptoms and psychosocial, existential, and spiritual issues," arising from a "sense of impending disintegration of one's person" or a loss of meaning (Darilkova 31). The hospice nurse, in their own vulnerability, understands that it is precisely through the patient's fragility that the deepest work of death care takes place.

APOPHATIC INQUIRY IV:

THE LIMINAL SELF

The Inner Space

Where does the moral and ethical obligation to ensure patient autonomy originate and should status or authority trump the relationality of patient autonomy? My upbringing sways me to the side of Kant’s Categorial Imperative, his central moral principle of absolute and unconditional duties. All humans possess intrinsic worth, which we call dignity. To interfere with one’s autonomy (self-rule) is to also undermine their dignity. For Kant, autonomy and dignity are tightly linked. I cannot agree more. Is there a place for Kant in relational care, especially at the end of life? Yes, and no.

I continue to struggle with this ultimate question; did Althea’s physician act in a way that any person would act in this same situation? To unilaterally decide to hang an IV of morphine, allowing her to “fade away” should make any individual cringe at such words. Here, paternalism displaced dialogue, reducing Althea’s agency to a physician’s paternalistic judgment. The Categorial Imperative would not hold up under this test. If I were to view it from the standpoint of relational death care, Kant helps me name the violation, but it does not fully capture the relational complexity of end-of-life decision-making.

And what of the legal ramifications of her physician’s actions? Laws are based on philosophical principles, in place to ensure a stable, safe, and just society. As society becomes more technologically advanced, it often struggles to keep pace intellectually, morally, and emotionally. Innovations in medicine, artificial intelligence, and biotechnology can extend life or even hasten it, increasing the amount of difficult choices we must make.

The action Althea's physician took was an example of paternalism in medicine. He had the authority to implement a technology that would provide Althea with complete pain relief, which in turn hastened her death. Unfortunately, the legal safeguards that were in place to ensure informed consent did not appear to hold. At some level, I understand how her physician desired to provide Althea with comfort. What he may have failed to do was provide ethical death care when her autonomy was circumvented.

The Aesthetic Space

The moon cannot shine without the sun. The sun reflects off the moon, enabling those on Earth to wonder at the details of its surface in all its roughness and beauty. Like the moon, the self reflects its relationship with others. Liminality is ever-shifting, existing in phases, holding together light and darkness, pulling us into new rhythms, and offering a reflective threshold between what was and what is yet to be.

Hospice patients float in this space of liminality as they transition from life to death. The dying body fades from Earthly existence while remaining illuminated by its relationship to others as it also finds its place among the stars. In this space their vulnerability is protected by the hospice nurse as the patient waxes and wanes between acceptance and denial, peace and fear, release and holding on. Like the moon, the patient continues to reflect the shadow and the light of their world. The moon is nothing without the sun's reflection, just as the self is nothing without others - *the between*.

This is the basis for the argument of relational autonomy. While decisions are made by the individual, thus making them autonomous beings, these decisions and their outcomes are not isolated from others. The apparent paternalistic decision of Althea's physician to administer a morphine drip, allowing her to "fade away" while understandable within the framework of biomedical ethics and the intention to act in her best interest, ultimately deprived Althea (moon) of the opportunity to make a choice in dialogue with, and in reflection of, her son (Sun).

"Liminality" watercolor. Denise Gawley 2025

<u>The Wondrous Space</u>

Where does the care covenant between patient and physician begin? Is it at the first clinical encounter or in the slow building of trust over time? Even if it evolves, can a physician truly come to *know* their patient through clinical sessions that last thirty minutes, likely less, on a weekly basis? What does it even mean to know a patient? Is it to memorize their chart, to observe their symptoms, or to listen for their deeper story? There really is no true way to know another than in the liminal space created in relationship.

Determining what it means to "do good" in these moments is rarely straightforward. Physicians are trained to alleviate suffering and protect life, yet the authority to define what constitutes harm or benefit is not always clear. At times, the desire to act in a patient's best interest can blur the boundary between care and control, particularly when decisions are made without the patient's clear consent. The ethical challenge for clinicians, therefore, is not simply whether to intervene, but how to listen to the patient's voice while navigating the responsibilities of care.

Conclusion

When decisions are made within the spheres of trust, vulnerability, and presence, autonomy becomes most humanized. Again, the I–Thou encounter resists objectification by affirming the patient as a whole being whose voice matters, even in dependence. To encounter the dying in this way is to uphold their dignity, not through isolated choice but through shared recognition. When paternalism prevails, or when institutional hierarchies silence the patient's voice, autonomy is stripped of its relationality and dignity becomes diminished. In these moments, it is not only patients who suffer, but their nurses, as well.

Moral distress arises precisely at the point where the nurse perceives the slipping away of patient dignity but is unable to act upon it. The sudden transformation from I–Thou into I–It becomes a wound carried by the nurse almost as much as by the one who is dying.

Autonomy takes shape through the process of informed consent, where the patient's right to make decisions about their own care is legally documented. Informed consent is more than a procedural requirement; it represents the moral power of dialogue between clinician and patient, where information and trust converge once again.

Althea was denied her inherent right to dignity when her physician chose to speak and act on her behalf, even if his intensions were to *do good*. There is no doubt that the morphine infusion provided her relief from pain, and this is surely a good thing. Her physician’s actions, resulting in the failure to provide Althea and her son with clear choice and understanding through dialogue was not.

APOPHATIC INQUIRY V:

RECLAIMING VOICE

The Inner Space

When is it morally and ethically acceptable for paternalism to over-ride informed consent? Here lies the point in time where Althea's human dignity was usurped by the paternalistic behavior of her physician. As well, here marks the heart of my moral distress. It was emotionally paralyzing to be told that Althea was going to be hooked to intravenous morphine and allowed to "fade away." My head was filled with a cacophony of voices that spoke no words, while all along screaming at the unethical and questionable legalities of what I was witnessing.

What the physician likely believed was proper medical intervention was, in truth, a collapse of autonomy, beneficence, and justice. From the standpoint of care ethics, it was the negation of attentiveness and responsiveness, which is at the very heart of nursing. My body reacted in emotional disgust as it fled the scene.

The professional obligation and ethical commitment I had to Althea was severed, while at the same time colliding with the actions of her physician. In that moment, I learned how betrayal does not only come from an individual but from the silence of others who allow such decisions to stand unchallenged. The words "fade away" remained in my psyche, as they say, "rent-free" for years, as did my director's response, "not another one." The cost of these remarks was actually not free. How many other times has the ethics of care of the dying been fractured by this medicalized death care system?

The Aesthetic Space

The true weight of what occurred soon sank in. I was facing the legalities of a procedure without consent that resulted in the premature death of a human being. Althea was a valued someone. She most assuredly was a mother and part of a family and community story that was not allowed to participate in her last chapter.

I knew how her ending was going to be written, and I was resentful and fearful for what part I may have played by not doing more. Althea had been seen and heard as an It rather than met as a Thou. This encounter was not neutral. It diminished Althea's true being. That shift, hidden in euphemistic language and medical orders, left me hollowed out and haunted.

Making matters worse was the intimidating tactics by superiors while I attempted to continue my work as a hospice nurse with this organization. It was clear that I needed to move on from this employer, if not hospice altogether. The foundation on which I predicated my practice in death care had cracked like the tectonic plates in Iceland - deep, sharp and stretching far into the horizon. Pieces of all I had relied on and understood just rolled down and crumbling away into the chasm.

Nursing embodies the profound recognition that dignity is preserved in relationship. Choice and consent are not reduced to a check box of **Yes** or **No.** When the covenant of ethical care is broken due to loss of dialogue and shared decision-making, or when institutions silence rather than support, both patient and nurse fall victim to authority.

Death care and informed consent involve choice, relationship, and vulnerability in union. We must consent. If we do not, we risk becoming just another victim. Hearts hang from IV poles, intersecting with the contents of dignity leaking onto the floor as Athea "fades away." The leakage of this love turns (or fades) to black as Althea's dignity is allowed to fall to the floor in a puddle of sadness and grief. The ability and right to autonomous choice, even if to mark the proverbial box of consent, alluded her. Just as my ethical commitment to my patient also spilled out into moral distress.

"I Do Not Consent" watercolor. Denise Gawley 2025

The Wondrous Space

The phrase "fade away" appears as a euphemistic cloaking of the action of stripping away of Althea's agency. It not only dulled her pain, but also silenced the voices of those who loved her. Did her physician act paternalistically in favor of compassion or convenience? Did he allow his personal bias of end-of-life care influence or even dictate how Althea's life would end? Is there still a place for paternalistic action in today's health care environment? Why are institutions of health still dominated by the philosophy of care that too often ignores the relational aspects of our humanity in favor of the medical doctor's final dictate?

Perhaps it is time for informed consent to be reconsidered not just as a transactional formality but as a relational practice that can somehow include language that allows for and honors decisions that are made within webs of relationship, trust, and vulnerability. Care ethics reminds and demands that dignity be preserved through attentiveness, responsibility, and responsiveness. This form of *relational informed consent* therefore requires more than information disclosure; it calls for dialogue that includes others, safeguards autonomy and dignity, and recognizes the patient as a whole being in relationship.

Conclusion

Relational autonomy serves as the ethical foundation upon which informed consent is built. To respect autonomy is to acknowledge individuals as self-determining agents in relation to others, capable of shaping the course of their own lives and, critically, their own dying. In health care, this principle becomes tangible through the practice of written informed consent, which ensures that patients are provided with the information, time, and space necessary to make decisions aligned with their values and beliefs.

Without relational autonomy, informed consent loses its moral force, collapsing into a mere formality rather than a meaningful dialogue. In this way, informed consent can be understood as autonomy in action: the visible, lived expression of respect for the patient’s right to participate in choices that touch the deepest aspects of their being.

The case of Althea makes clear that informed consent cannot be reduced to a legal ritual or an institutional safeguard. When her voice was silenced without dialogue, what was lost was more than procedural. What was lost was her dignity, her relationships, and my own ethical grounding as her nurse, causing me to experience moral distress. To consent without conversation is not to consent at all; it is to fracture the trust that should anchor all care, especially at the end of life.

What happened with Althea is not an isolated failure but a symptom of a medicalized system that struggles and often fails to see the dying as relational beings. To restore informed consent to its rightful place is to resist paternalism, resist reduction, and resist the silencing of those most affected. It is to affirm that the final act of care is not technical but ethical: bearing witness to the patient's dignity.

PART IV: UNFOLDING

Throughout this dissertation, I have explored the safeguarding of dignity in end-of-life care through literature review, narrative, philosophy, and apophatic inquiry, as well as the moral distress that can arise within these encounters. Yet the dimensions of death care, particularly those connected to relationships, vulnerability, voice, and witness, continue to resist full articulation. To attempt a more complete explanation would risk diminishing their ethical weight.

Working thematically rather than narratively, my artwork expresses the recurring conditions of dying: presence and absence, listening and silencing, holding and releasing, agency and resignation. In this way, my artwork participated in the apophatic practice, functioning as what Curt Cloninger describes as "mechanisms for contemplation" that provoke and welcome questioning rather than confirm what is already known (108–17). The images do not attempt to resolve meaning but instead remain with what cannot be fully explained.

As a nurse, I often find myself positioned as both witness and evaluator. The strength of holding firm convictions about right and wrong does not always serve me well. Humility becomes necessary in recognizing that I am not the only one present within a given situation, and that as a nurse I remain, in many ways, an outsider to another person's experience of dying. It is difficult to witness what appears to be injustice and feel unable to advocate effectively, particularly when such moments seem to occur with unsettling frequency within contemporary American healthcare.

In reflecting on this role of witness, a symbolic image began to emerge. In Celtic mythology, crows are associated with the battlefield goddess Morrígan, appearing at moments of death and transformation. In this sense, I recognize myself as the crow, present as witness, engaging where I am able. Perhaps I function less as a participant and more as a mediator within the transition to death. If this is so, I must allow myself the grace of relinquishing control and accepting that I cannot make everything “right.”

My experience of moral distress surrounding Althea’s care gradually revealed more than a single ethical quandary. It exposed the broader cultural and institutional forces shaping contemporary death care. Through this inquiry, I began to recognize how medical authority, technological intervention, and institutional routines can distance caregivers from the relational presence that safeguards dignity. This realization was not a dramatic awakening but rather a reminder of how deeply embedded these forces have already become and how intentionally relational care must therefore be protected.

Surrendering to vulnerability is not weakness but ethical strength. Through reflection on this experience, I have come to understand that ethical care at the end of life does not arise from mastery or control but from the willingness to remain present within shared vulnerability. In this sense, vulnerability becomes an act of moral courage, allowing relational presence to safeguard dignity even when medical explanations and interventions fall short.

I have come to recognize moral distress as a form of ethical awareness; a signal that something morally significant has been disrupted. Meeting Althea within the liminal space of her transition to death was not a burden but a recognition of my commitment to safeguarding dignity at the end of life. Within that space, dignity is not protected through clinical intervention alone but through relationships and the willingness to remain present when the world beyond the liminal threshold feels chaotic.

Perhaps the deeper source of my moral distress was witnessing the loss of Althea's voice; her autonomy. It was not only the clinical outcome that troubled me, but the sense that her expressed desire to return home to die had not been fully honored. This experience revealed the fragile nature of voice at the end of life as the mind and body weaken. In these moments, the ethical responsibility of clinicians and caregivers to safeguard and uphold the patient's voice becomes even more significant.

The *Code of Ethics for Nurses* (American Nurses Association 2025) affirms both the right to patient self-determination and the vital role of nurses in end-of-life decision-making. While advance care planning and resuscitation discussions are routine in many fields, hospice nursing involves a unique moral task: assisting patients to navigate the existential experience of their body's final relinquishment.

Again, as the continued most trusted profession in the United States (Walker 1) nurses also bear the deepest impact of institutional ethical failures. Nursing has always been a moral endeavor grounded in truth-telling and advocacy (Corley 637). Far from being the physician's handmaiden, the nurse is a champion of justice, accountability, and relational care. For hospice nurses, this advocacy defines the work, as the dying are among the most vulnerable within the health care continuum.

The case of Althea illustrates how these ethical complexities converge. Her physician's actions resembled palliative sedation, a last resort intervention meant only for refractory symptoms when death is truly imminent and informed consent is obtained (AMA). In her case, I do not believe these ethical conditions were met: her symptoms were not clearly intractable, death was not imminent, and consent was not demonstrated.

This was not simply a difference in clinical style or practice, but a failure of relational ethics due to a breakdown in dialogue, transparency, and shared moral responsibility.

Could Althea's physician have had the intention of compassion? Or was his decision an expression of medicalized control, allowing Althea to "fade away" rather than to allow for accompaniment through the dying process? These questions persist because relational care was missing. Time was not taken to listen, to understand, or to act upon Althea's expressed wish to return home.

There is nothing medical about the final breath, as it is wholly human. When I enter the home of a dying person, the air thickens and time slows. I hear with my eyes more than my ears. In these moments, silence becomes a form of truth-telling. Presence itself becomes language. The intimacy of death work often leaves nurses isolated, with little institutional or peer support. This "moral suffering" emerges when one cannot act upon deeply held ethical convictions (Rushton and Boston-Leary 102). It is not merely burnout, but a wound of conscience; a fracture of moral identity.

Through apophatic inquiry, I have come to see moral distress not as a professional failure but as revelation. I am beginning to feel freed from the grips of anger and guilt, understanding that sometimes there are just no answers, no words, no rationale for what just is.

Relationship, meaning, and voice matter and must not be allowed to erode. The encounter with death reveals who we are and how we are with others. It is both a professional and profoundly human reckoning. To successfully care for those who are dying requires relational awareness, moral humility, and the courage to remain present in uncertainty. Only then can we begin to reclaim the mystery of dying from medicalization and to honor life by allowing a dignified *fading away*.

When autonomy falters, bodies weaken, and language runs out, dignity is safeguarded not through control or intervention but through the quiet courage of those willing to remain in relationship, bearing witness to the humanity that persists even in life's final breath.

"Making Sense of it All" watercolor. Denise Gawley 2026

CONCLUSION

This dissertation underscores the paramount importance of a relational approach to death care as a means of safeguarding patient dignity at the end of life. The prevailing bioethical framework too often sustains conditions in which ethical injustices occur, conditions that are also a primary source of moral distress for hospice nurses who bear witness to them.

Through the combined lens of Martin Buber's dialogical philosophy and apophatic inquiry**,** I have explored what it means to care ethically for the dying when traditional frameworks and institutional practices fall short. The case of *Althea* revealed how easily dignity can be lost when autonomy is reduced to procedure and how moral distress in nurses arises not from personal fragility but from a profound awareness that something ethically deep has been compromised.

Relational death care calls for a shift from viewing autonomy and ethics as the property of the individual toward understanding them as relational practices sustained through dialogue, recognition, and presence. When the dying person is encountered as a Thou rather than an It*,* dignity can be maintained. When the nurse's moral agency is honored rather than silenced, the capacity for ethical care expands. Both the *cared-for* and the caregiver are preserved within the integrity of their relationship.

Apophatic inquiry has served as a reflective method for engaging what cannot easily be named, such as the moral and spiritual residue that lingers after experiences of ethical injury. This method of discovery offers a way for nurses to acknowledge and even embrace silence, uncertainty, and vulnerability as legitimate forms of knowing that can lead to healing. It does not seek *to* resolve moral distress but to engage with it. Within hospice care, this orientation invites reflection, dialogue, and creative expression as tools for moral resilience and understanding.

Ethical care must encompass both symptom management and relational presence. Safeguarding dignity at the end of life requires practitioners to remain attuned not only to pain and comfort but also to recognition, trust, and meaning. This dissertation argues that moral distress can also serve as a moral compass**,** guiding clinicians toward what matters most in ethical practice: dignity, honesty, and relationship.

This dissertation contributes to the growing body of scholarship in nursing ethics and end-of-life care by offering a relational framework for understanding nurse moral distress within contemporary death care. The findings suggest that moral distress is not merely an individual psychological burden but an ethical signal arising when relational dignity is threatened. In recognizing moral distress as a form of ethical awareness rather than professional weakness, this study offers a new lens through which nurses, educators, and healthcare institutions may better understand and respond to the moral realities of caring for the dying.

By restoring relational dialogue to end-of-life care, we restore the humanity that medicalization too often displaces. The dying deserve more than competent symptom control; they deserve to be known. And those who care for them deserve systems that support, rather than silence their moral voice. Care for the dying is not merely a clinical task but a moral and relational act of love; a reminder that ethical care is sustained in the space between nurse and patient, where dignity is recognized and humanity is shared.

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