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When Moral Uncertainty Becomes Moral Distress

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Introduction

The Many Faces of Moral Distress Among Clinicians

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Abstract. This narrative symposium illuminates the problem of clinician moral distress. *NIB* editorial staff and narrative symposium editors, Cynda Rushton, PhD, RN, FAAN and Renee Boss, MD, MHS, developed a call for stories, which was sent to several list serves and posted on Narrative Inquiry in Bioethics' website. The request for personal stories from inter-professional healthcare providers asked them to: identify specific clinical situations that give rise to moral distress; discuss the sources of this distress; reflect on how they experienced moral distress—physically, psychologically, socially, or spiritually; assess how they managed their situations; and offer suggestions for avoiding future problems of a similar nature. Twelve stories are found in the print version of the journal and an additional eight supplemental stories are published online only through Project MUSE. The clinicians describe a wide range of experiences with patients, other clinicians, and their own professional and personal identities. Embedded in each of the narratives are deeply felt emotions that accompany their experiences of moral distress. Katherine Brown-Saltzman (a nurse), Alisa Carse (a philosopher), Zhanna Bagdasarov and Shane Connelly (industrial-organizational psychologists), and Nancy Berlinger (a bioethicist) provided commentaries.

Key Words. Bioethics, Clinicians, Inter-Professional Team, Moral Distress, Moral Uncertainty, Narrative Symposium, Negative Emotions, Value Conflicts

Moral distress is a reality of clinical practice that impacts all members of the inter-professional team, the quality and safety of patient care, and the sustainability of the workforce. Described initially by Jameton (1984), moral distress reflects the deep commitments and value conflicts that accompany their professional roles and the complex patient and family situations they confront. Although the initial focus of research was on nurses working in high intensity settings

such as critical care, we have learned that moral distress is a pervasive experience across clinical roles, settings, and specialties. The existence of moral distress has been repeatedly documented, but to date effective strategies to mitigate the detrimental effects have not been fully identified. The focus of this symposium is to illuminate the impact of moral distress on clinicians from a variety of perspectives. We asked inter-professional colleagues to identify specific clinical situations that give rise

to moral distress and their sources and to reflect on how they experienced moral distress—physically, psychologically, socially, or spiritually. We then invited story authors to reflect on how they dealt with their moral distress and proposed a series of questions to stimulate their exploration.

- What actions did you take that allowed you to uphold your deepest values?
- What were the conditions within yourself, the people involved, and the external environment that allowed you to do this?
- What ongoing worries do you have that you were not able to uphold some of your values?
- How have your own values evolved as a result of moral distress experienced in your role as a clinician?
- How have you made sense of the situation?

We asked them to identify the short or long term consequences including job commitment and performance, disciplinary action, and residual impact. Finally we invited them to propose ways they would change the system (e.g., policies, hierarchies, processes) to alleviate moral distress within their position?

We recruited inter-professional clinicians to submit their narratives of moral distress from bioethics list serves, invitations to targeted high risk groups, a call posted on the journal's website (<http://www.nibjournal.org/>), and other social media outlets. We received nearly 40 submissions. Of those, 12 were selected for inclusion in the Symposium and another eight are included in the online version of the journal available on Project MUSE (http://muse.jhu.edu/journals/narrative_inquiry_in_bioethics/). The choice of stories for the issue was based on many competing factors: a male vs. female perspective, a need for stories from various types of healthcare professionals, and interest in stories that highlight various types of situations and responses, etc.

Commentaries from a nurse (Katherine Brown-Saltzman), a philosopher (Alisa Carse), two industrial-organizational psychologists (Zhanna Bagdasarov and Shane Connelly), and a bioethicist were invited (Nancy Berlinger). Each of the commentators illuminates important dimensions of the terrain of moral distress and offers useful insights.

The Many Faces of Moral Distress: Themes and Insights

The clinicians, who write so compellingly of their experiences in this issue, describe a wide range of experiences with patients, other clinicians, and their own professional and personal identities. While the individual situations are often quite different, ranging from intimate moments at a dying patient's bedside to very public humiliation at the hands of a co-worker, each illuminates the lived experience of morally distressing events. Embedded in each of the narratives are deeply felt emotions that accompany their experiences of moral distress. Predominant emotions described in the narratives include anger, fear, disgust, sadness, and humiliation. Negative emotions such as these can be unregulated and intensely experienced.

Bagdasarov and Connelly examine the consequences of unregulated negative emotions through the lens of emotional labor. They propose: "the presence of unregulated negative emotions will likely limit individuals' ability to recognize their inherent complexity and, subsequently, hinder their ethical decision-making." If this is true, attention to the somatic, emotional and behavioral responses to morally distressing situations could alert clinicians to signals that accompany unregulated emotions and the potential threat to their ethical decision making capacities (Rushton, Kaszniack, & Halifax, 2013b).

As Carse writes, "Many of these narratives bring us into visceral contact with what it is like to feel trapped, constrained, pressured, or lost in a situation that acutely challenges one's ability to sustain moral integrity despite one's best efforts to do what is right." She highlights the moral disempowerment that often accompanies moral distress when it is silenced and unprocessed producing humiliation, infuriation and isolation that lead to feelings of shame and guilt. Brown-Saltzman similarly highlights how "the combination of isolation and dismissal play a major role in accentuating the effects of moral distress that often lead individuals to become silent." When clinicians become voiceless and silent about issues that threaten their integrity, the quality and safety of clinical care is threatened.

Both Carse and Brown-Saltzman point to the impact of accumulated distress in the dramatic cases and in the day-to-day conundrums of clinical practice where integrity begins to erode when seemingly small violations begin to mount with unrelieved constriction of moral agency and as Berlinger proposes, shapes professional identity. The cumulative and intense consequences of moral distress provide sufficient justification for focused and sustained attention to addressing its underlying causes, symptoms, and to designing comprehensive methods to address them.

Although most emotional responses to moral distress are cast as negative emotions, positive emotions of gratitude, acceptance, and love are also conveyed. Arguably, the majority of the cases involved at least an initial activation of empathy toward the predicament of the other and yet over time, it becomes transformed into feelings of failure, self-loathing, despair and anger.

We are left with considering how we can rehabilitate our responses to moral distress in ways that allow us to reconnect to our capacity for empathy and compassion instead of resorting to attempts to relieve our distress that may undermine further our wholeness and well-being (Rushton, Kaszniack, & Halifax, 2013a). Bagdasarov and Connelly, for example advocate for helping clinicians to move beyond organizationally prescribed and sanctioned ways of dealing with one's emotions to more authentic recognition and expression of one's feelings by using methods such as cognitive re-appraisal to shift one's perception of the situation. These shifts are thought to enhance personal and professional outcomes such as job satisfaction, enhanced job performance and retention.

An interesting insight into the to the experience of moral distress is the dimension of time. Katherine Brown-Saltzman states "the elements of time are revealed in many facets: in the need for efficiency, in avoidance of the difficult discussions, in how the experiences are implanted into one's core and unfold over time." Brown-Saltzman and Berlinger question the source of urgency to act when confronted with morally distressing situations. One wonders whether the urgency is created by the

temporal requirements of the clinical situation or whether it might be fueled by the overwhelming need to find relief from the painful feelings associated with the moral distress. Being able to differentiate these elements of time and urgency can open the door to designing alternative strategies.

Transforming Moral Distress: From Disempowerment to Effective Agency

A central theme of this issue, and of each narrative, is the need to develop personal, professional, and organizational strategies to transform moral distress. For most of the authors, these strategies were found by trial and error, by a personal intention to bring something good out of a distressing situation or arguably, as a means to relieve their own uncomfortable feelings and disperse the residue. And yet, moral distress is a predictable event in health care, an event that will likely recur many times and in many ways. The reality is familiar. Patients and families are often stressed, traumatized, overwhelmed, and ill. Clinicians are often stressed, fragmented, tired. Disease outcomes are often uncertain, unpredictable, and difficult to control. These contextual features create the conditions where moral distress can thrive. Given the high stakes outcomes of clinical care every effort should be made to decrease the incidence of moral distress, and many additional resources should be directed to helping those who experience moral distress to overcome and transform the distress into personal and professional resilience.

There are several important and critical themes that highlight how individual clinicians can transform moral distress into advocacy, growth, and resiliency. Carse, for example, highlights the ability of some authors to preserve their moral agency in a way that retains integrity. Pnewski, for example, articulates a dynamic process of self-effacement, reflection and courageous action that ultimately allows her to be in the midst of a morally distressing situation without being overcome by bitterness, anger or resentment. As Humphrey described, finding a way to make peace with the daily moral uncertainty of clinical work is an important

antidote to the feelings of powerlessness that can overwhelm one's desire to heal the maladies that patients live with, serve others, alleviate suffering, and support healing.

One strategy, described in the narratives, is self-empowerment through gaining additional skills and competency and assuming positions of authority to redress some of the sources of moral distress. For several authors, their personal experiences of profound discord between what did occur and what ought to have occurred often led them to seek more training and expertise in ethics, either by joining hospital ethics committees, pursuing certificates or degrees in bioethics, or seeking out institutional training in bioethics. Expanding one's repertoire of knowledge and skills builds competence and confidence in more proactively addressing the sources of moral distress.

Many of the authors tell us of the critical importance of supportive people who helped to share the intellectual, moral, and emotional distress of these experiences. Many people talked of the need for family members and friends to care about and for them during the time when they felt most distressed. But just as importantly, people spoke of the relief they found in supportive co-workers and supervisors, colleagues who could understand the occupational context for the moral distress, who could share similar experiences, who could offer advice. These supportive individuals were often key to the ability of clinicians who were experiencing moral distress to continue to work and to process their feelings. It is also notable that these supportive individuals came from within—and outside of—the clinician's own discipline or role. That is to say, doctors were supported by nurses; nurses were supported by students; trainees were supported by other trainees. Given the interdisciplinary nature of many health care organizations, it is not surprising that important supports develop between individual clinicians of all backgrounds, even as it remains common for organizational supports to be more narrowly focused on single disciplines. Nursing staff are often offered channels for support from other nursing staff; social workers are directed to social work staff. This suggests that a key element

of creating an environment where moral distress is addressed effectively is to engage the inter-professional community to examine how they might contribute individually and collectively to a culture where support for one another is normative, valued, and appropriately resourced.

Another way that these supportive colleagues were key to clinicians' abilities to transform their moral distress seemed also to be via acknowledgement and validation. During and soon after a distressing event, individual clinicians often wondered if their reactions were warranted, if their perceptions were accurate, if they were overreacting or misinterpreting. Multiple authors write of feeling disoriented, confused, uncertain, at times feeling almost unreal. Because many of the distressing events involved clinicians who were alone, who heard or saw something that others did not, who had perspectives others did not share, an initial reaction to their discordant thoughts and feelings was to question if they were valid and accurate. Validation from supportive colleagues that a problem had occurred, that an error or a policy violation or an act of negligence had in fact taken place, was an important part of a clinician's ability to manage the incredulity and blame that initially prevented action. This step helped clinicians to find their voice and begin the process of taking steps to address their moral distress. Naming their moral distress and finding a voice to speak about it parallels the phases of suffering described by Warren Reich (Reich, 1989)—mute, expressive and transformative suffering. One of the challenges in designing interventions to address moral distress is to find strategies to help clinicians to move from their muteness and arguably, their unconscious awareness of the source of moral distress, to being able to speak about it and begin to make sense of their experience. Bringing voice to the distress and having others to validate its importance, impact and meaning is crucial to helping clinicians transform their negative feelings into effective agency.

Carse proposes a kind of "resilience of moral agency: that calls for attention to the individual and structural contributions to the experience of moral

distress. Comprehensive strategies to transform moral distress will likely need to include both; neither is sufficient alone to produce the kind of fundamental transformation that is called for. Bagdasarov and Connelly, for example, introduce the interesting concept of emotional labor, “the process of regulating both feelings and expressions for the organizational goals (Grandey, 2000).” They advocate for more robust emotion regulation strategies to counteract the negative health outcomes for clinicians. These, coupled with systemic mechanisms for reflection and creating meaning, a place for acknowledgement and bearing witness to each others suffering (Carse), seem to be fruitful areas for intervention. An additional benefit of such methods may be to help clinicians who are morally distressed to regain the stance of neutrality that Brown–Saltzman advocates for.

The question remains: Is moral distress an inevitable and inescapable dimension of contemporary health care? One might theorize that moral distress is inevitable and that there are individual and systems opportunities to modify the individual responses to the moral distress, design systems to recognize, name and address the sources and root causes of moral distress, and to build resilience and hope within a constantly changing, complex health care system. Our hope is that this symposium will contribute to a deeper exploration of the impact of moral distress, to examine the root causes of the situations that spawn moral distress and to engage creativity and innovation to design effective and sustainable solutions.

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Personal Narratives

What Power Do I Have? A Nursing Student's Concerns Lead to a Passion for Ethics

Anonymous One

The day began like many in our ten-week rotation, around the large table in the brightly lit ICU nurses' station. Report, which was given by the night charge nurse, included information on all the patients on the unit. Since I had cared for A. G. the previous day, I was eager to know how she had spent the night. She had a debilitating neuro-muscular disease known as myasthenia gravis. Placed on the ventilator days before, it was reported that she was likely to be dependent on the machine for life. In the late 1970's there were very few facilities that accepted ventilator dependent patients. She might be with us for a long time.

When I entered her room for the first time, I saw a frail older woman with kind eyes and a warm smile. She was breathing with the help of the ventilator through her tracheostomy tube. I learned through her chart that she had no known family. On the day I took care of her, no one came to see her and she had no visitors the previous evening. She lived in a local long-term care facility and was brought to the hospital after she developed respiratory distress. A. G. was unable to move in the bed due to her condition and required frequent suctioning along with turning and repositioning for comfort.

Despite her weakness, A. G. was able to communicate silently by mouthing the words for what she wanted and by nodding and shaking her head. I found her to be quite skilled in non-verbal

communication since it took minimal effort to understand what she wanted, but the activity tired her easily. I had just completed A. G.'s morning care when her physician came in to examine her. After completing his assessment, he stopped and leaned in closely to speak with her. He began asking a number of questions about whether she wanted to spend the rest of her life in this way, on a ventilator. She shook her head. Continuing the line of questioning in different ways, she responded to him. I wondered why he was asking these questions. After seeing her response, the physician asked me to get 30 mg of morphine from the narcotics cabinet. Although I didn't understand the implication of the request, I complied.

While I was retrieving the medication from the narcotics cabinet, the charge nurse came to tell me I was being reassigned to a new admission. When I asked why, she told me she couldn't discuss it, but asked me to please do what she said. I left her standing there, wondering what was going on. After assisting with the new admission, I went back to see A.G.; her door was closed. When I opened the door, the ventilator tubing hung over the side of the machine. Looking down at the bed, I was shocked to find A.G. had been disconnected. She was dead. In a state of disbelief and panic, I sought out the charge nurse to find out what happened. It was clear that I was not to know. I asked her a number of questions but she adeptly changed the subject and redirected me to other activities. By then it was lunchtime and my instructor had left the unit. I asked to be excused and went to seek her out.

When I told my instructor what happened, a look of doubt came over her face. "You think Doctor M. killed your patient? That would never happen." Although I tried to tell her the story, she too, dismissed me, telling me my story didn't make sense. I was distraught. An overwhelming sense of dread came over me and I began to cry. She encouraged me to go home, which I did.

Happily, I had the weekend to recover before returning to clinical. I never found out what happened to A. G. and neither my instructor nor the charge nurse ever spoke to me about my experience. In fact, it seemed no one believed my story. Although my classmates heard my distress and the

anger that eventually ensued, they cautioned me to let it go and get to graduation.

A part of my innocence was lost on that day. My belief in the good of others, especially nurses and physicians was challenged. Distrust, concern that maybe nursing wasn't for me, fear that the truth would be discovered and I would be reprimanded, or worse, interrogated, were worries I struggled to overcome. I was 21 years old. What power did I have to prevent this from happening to others? This was a question I would consider over and over.

After graduation I took a position in another hospital but soon realized I preferred working in the hospital where I went to nursing school. So I went back and was offered a position in the ICCU. Although I was now months beyond the death of A.G., the experience never left me. As an RN, I was committed to discovering whether my situation was an isolated event, or a common occurrence. I never wanted what happened to me, to happen to anyone else. In fact, the first change I made in my practice was to "debrief" with the nursing students after a patient death. It was my belief that a student should never go home without understanding and talking about the death of his or her patient.

Over time, I was promoted to positions with greater responsibility, nurse manager, critical care educator, critical care director, and ultimately to the position of chief nursing officer. Each position offered me the opportunity to monitor end-of-life situations in some way. As a manager in a related department, staff would report any concerns, which would result in follow-up on my part. In an educator role, ethics and advocacy were taught and supported. Patients were to be protected. The director role allowed me to monitor the quality of care and to create policy. Ultimately, in the CNO role, the responsibility for patient care stopped at my position, a position I took very seriously.

In a parallel process, I believed it was important to gain more knowledge in ethics. Taking an ethics course in graduate school allowed me to look back on my distress to help make sense of it. Consent, capacity, decision-making, all were necessary to understand A.G.'s death. In my director and CNO roles, I became part of the organization's ethics committee. Becoming a committee member gave

me input into policy making and decision making, another way to advocate for patients.

Eventually I left the organization to pursue a PhD in nursing. My dissertation was focused on end-of-life experiences and my elective courses were centered on ethics related topics. Ethics had become my passion.

After graduation I was offered the opportunity to practice as a healthcare ethicist. Working closely with ICU staff in a large teaching hospital, I had the chance to assist nurses experiencing ethical challenges. Whether through education or by rounding in the ICU, I was accessible to staff for consultation or for debriefing after a difficult case. Often, implementing good communication practices was the most effective in averting moral distress and resolving morally problematic situations. My position also included teaching ethics courses to graduate students, a role I still enjoy today. The adage, “knowledge is power” holds true in ethics.

Currently I’m pursuing a master’s degree in ethics, hoping my degree will help me find ways to prevent situations of moral distress, or to at least find opportunities to mitigate them. There’s so much work to be done.

It’s been 35 years since my encounter with A.G. As I think back on that day, I realize she may have made a fully informed decision with full knowledge of what was to happen. If that was the case, perhaps much of my distress could have been avoided if someone had taken the time to talk with me and to explain. Transparency is a word I have come to appreciate.



The Sanctity of Life—the Sanctity of Choice

Kristina Hallett

What do you do when helping someone means advocating for his death?

I am a Board Certified Clinical Psychologist and have been in practice since 1993. I

entered the field, as most do, to be of assistance and support to people in dealing with the difficult, the unimaginable, and the often painful circumstances of life. The goal has always been simple: to help. The manner may differ, but the central goal is the same: to help. I have encountered many challenging situations in my work: times when I felt unbelievably sad upon hearing someone’s story; when I felt righteous indignation at injustices encountered; when I worried for someone’s safety; when I laughed and rejoiced in someone’s experience. In each of these situations the path to helping was clear of moral dilemma. But what about when helping results in execution – the state enforcing the legally imposed punishment of the death penalty? While some decisions involve the potential for moral and emotional distress, there is usually a way of understanding “helping” as giving voice to an individual’s right to choose. What do you do when helping someone means advocating for his death as punishment?

Several years ago while I worked for a state Department of Corrections (DOC), an inmate on death row was executed. The state had not conducted an execution for decades. I was the Supervising Psychologist for the DOC facility, and as such it was my role to facilitate mental health treatment for this inmate. I was also the liaison to DOC custody staff regarding policies, treatment, and the impact of the process of an execution on staff, the involved inmate and other inmates in the facility. The DOC staffers were split in their views of the situation. Some staff were adamantly opposed to the death penalty, a portion were relatively neutral and the largest number of staff were strong proponents of the death penalty—some to the point of relishing the execution.

He had confessed and been convicted of heinous crimes, including the rapes and murders of several young women. Innocence was not a question. He readily admitted his responsibility for these crimes. The legal process was long and involved, including several different trials and penalty hearings, all with the same result: he was sentenced to death. Now all mandatory appeals associated with the death penalty were exhausted. Having already spent a great many years on death row, he did not want to pursue further appeals. He made the “choice” to

not file a voluntary appeal and instead to proceed with the death penalty process.

It is a curious thing, but when the required appeals (the checks and balances of the legal system) were completed and this man said, "I want to proceed with the imposition of my sentence," all the rules changed. This individual, who had been competent to assist in his defense and his appeals to fight his sentence for over twenty years, was suddenly seen as "incompetent" to choose to accept his sentence. Opponents of the death penalty viewed execution as "state-assisted suicide" and believed the inmate had "death row syndrome," and therefore was not competent to make the decision to move forward with his sentence. Those who agreed with the death penalty believed he was fully competent and supported the completion of his sentence through lethal injection. And then there was me.

I had always been against the death penalty. From a moral perspective, I believed in the sanctity of life, that we do not have the right to take the life of another human being. I shared in others' horror and outrage at horrific crimes, but felt justice belonged to the legal system (through incarceration) and to God. I did not believe in retribution or revenge, although I supported consequences and accountability. I argued against the death penalty in high school debates, college round-table discussions and in theoretical conversations with my peers, family and friends.

When faced with this situation as a psychologist, I found myself splitting a very fine hair. I did not support the death penalty, but I did support the ability of an individual to make a conscious choice. And I supported the right of an individual to be seen accurately, and to have his voice heard, even when his voice was raised in favor of his own death.

Multiple competency evaluations were completed for the prosecutor's office, for the public defenders office and another at the request of the convicted, who wanted to have his own "expert witness." Oddly, there was now an alliance between the convicted and the prosecutor, as both argued the case of mental competency in the affirmative. On the other side, the public defenders, the family of the convicted and interested other parties argued

that this man was *not* competent as a result of his many years of confinement on death row and moving forward with implementing his sentence was "state-assisted suicide."

I spoke with all of these individuals during this process. I talked to the psychiatric evaluators, the prosecutors and public defenders, the staff working in the correctional facility, the members of the religious orders, the friends and family members. I spoke with the convicted man on a daily basis, and listened as he poured forth his frustration at trying to prove he was sane enough to die. His reasoning was based in faith, developed over years of incarceration. He wanted to spare the victims' families further pain. He said he didn't want to die. Since he had lost all reasonable appeals for conversion to a life sentence, and knew that some day he would be executed, he did not want to continue to "drag the families" through the re-creations of his crimes that accompanied each court hearing. He spoke eloquently and at length about his religious convictions and his awareness of the unimaginable pain he caused so many people. And there's no denying that he loved the attention. He liked having a platform for his anti-death penalty views and he hoped to be a force for change. He hoped that with his death, the state would change the law and abolish the death penalty. He had a system of belief, and was also narcissistic, in the actual psychological sense. In fact, that was one of the arguments made against his being competent—that he was motivated by narcissism, rendering him unable to make a sound decision. With this case, even the definition of "competent" was challenged, moving away from "able to understand and participate in his defense" toward "making a reasonable decision." Which naturally led to the question: who determines what is a reasonable decision? Does the individual have the right to choose, even when their choice leads to the final choice of death?

The conflict for me was multi-dimensional. There had been too much death already—how would one more death help anyone? For those who sought "justice" and retribution—would their hearts feel any less empty with his death? Those precious lives were already gone, squandered

through the sick and twisted desires of the condemned. But what if it were my child, my sister, my friend who was the victim? What he had done was horrific. Would I feel the same way, still see his death as senseless? Would my heart and mind burn for him to suffer . . . and would I consider death to be a greater suffering than life inside an 8 by 9 foot cell? The argument regarding competency provoked a similar internal conflict. If you're willing to die at the hands of the state, are you wishing for death? Does a wish for death indicate an inability to reason—as if the only “right” answer is to always choose life? Is it possible to be entirely sane and competent, and choose death? And in particular, if this death is chosen as a means of notoriety, what of those “noble deaths”, the saints and martyrs who died for their beliefs? Underneath all of those questions was the idea of judgment. What right do I have to sit in judgment of others? Who am I to evaluate the “value” of their beliefs—to determine what's real, what's valid?

I had a job to do. I met with him, the staff, the lawyers, the priests and the family. Talked with my colleagues about their internal struggles, supported those who hated having any involvement in an execution, and tried to answer those who asked how I could see him every day and not look forward to his death. The planning, the listening, the discussions consumed my days. At home, my friends offered to listen to me, but I had no words. Simple descriptions of events took so long, and I couldn't seem to answer my own questions. Whose life did I value the most? Feeling alternately hypocritical and callous, I continued to do my job to support those involved.

The protests and legal challenges mounted, as so many in the greater community spoke out against the death penalty. As those voices rose, so did the voices of the victim's families, the outraged defenders of justice, and the voice of the condemned. He spoke about his right to choose, with a clear mind and compelling argument. I believed in his competency, and competency was the path to his imminent death by execution. The fallacy behind the argument for not being competent was the idea that he should appeal. Not an appeal based on new facts,

or a different interpretation, but an appeal made simply as a means of prolonging his life. Choose life at the expense of the truth, at the expense of those who had already suffered so much? Choose death, adding to the toll of losses that never should have been, through a decision against all I believed? Listening to each side of the situation, sharing perspectives radically opposed, I struggled to find my own center, my own way.

I found opportunities to reach out to others, assisting with activities in my community, at my church and with my family. When friends wanted to know “how are you”, I kept it brief, and focused on the concrete, shying away from further tumultuous explanation. There were moments of total clarity, when I knew exactly who I was, with no second, third or fourth—guessing of my motives and my morals—moments when I felt at ease in the present—and many other moments when I questioned every step of the process. The law had been made, the sentence given and the wheels of the legal machine were turning. I was not even a cog—I was part of the rocky road underneath the machine. My voice would not change the outcome, whether I whispered, shouted or was silent. I wondered if I had an obligation to take a stand, and that brought me full circle to questioning what stand I would take, should take, in these circumstances.

Some days I tried to balance the relative weights of choice vs. life. Other days I tried to not think at all and just do my job. Every day there was someone to support, someone to listen to, and someone to assist in exploring feelings . . . to help, because above all else, that was my job. To help others in whatever way I could, regardless of my own thoughts or feelings.

So how did I find my way? I walked the line between every explanation, understanding each one, in wholehearted agreement with none. I valued both the sanctity of life and the sanctity of choice. I went to what I knew, what was available to me. I lived and valued each moment of my experience. The moment became my truth, learning to tread water in ambiguity and ambivalence. I appreciated each opportunity to do what my training, and my heart, allowed me to do. I didn't

have my own answer, but I had a job, and a calling, and that's what I did.



To Nurse Better

Jaime Hensel

When things were quiet again I asked him what training he'd had to become the director of hospital security. "I worked for 20 years in corrections," he answered proudly, and I was saddened but not surprised.

In September 2010 I started an accelerated graduate entry nurse practitioner program to become a family nurse practitioner. Accelerated programs leave little time for preamble, since the idea is to take a total novice and turn her first into a nurse and then into a nurse practitioner in just three years. While the classroom information was vital, it was our clinical experiences that really initiated us into the profession. In just the second week of school, we were divided into small groups and assigned to clinical preceptors—hands-on teachers who introduced us to our first patients, curbed our mistakes, quelled our fears, and pushed and pulled and cajoled us into being nascent healthcare providers. In showing us how to give bed baths, suction secretions, insert Foley catheters, and hang IV bags, our preceptors really began showing us how to use our hands as healers.

In that first semester my patients also proved to be invaluable instructors. Talking to them, administering their medication, washing their bodies made me keenly aware of the delicate balance of vulnerability and power and trust and respect and intimacy that underlies all healthcare relationships. I hope, wherever those patients are now, they know how deeply I appreciate their patience and good humor and their collusion in my education.

In December, the first semester and the first clinical rotations ended. Four months into nursing

school I had a basic understanding of what it means to be a nurse. Frankly, most days I still felt like an impostor in blue pajamas sporting a stethoscope I didn't really know how to use and new Danskø clogs that squeaked with every step. But in an accelerated program, fast and furious is the name of the game. We went away for winter break—a much needed breather—and came back to something completely different: psychiatric nursing.

In preparation for these new clinicals, we were taught in class that we should not wear dangly jewelry or stethoscopes. That we should never let the patient get between us and the door. That psychiatric (psych) patients could escalate quickly; psych patients could have surprising triggers; psych patients could be very unpredictable. And psych patients could be violent. We were taught about physical and chemical restraints, and about show of force. We were cautioned, as students, to stay out of the way if things got tense on the floor. In stark contrast to medical patients, psych patients were made to sound less like people who had diseases and more like adversaries. I drove to my first day on the floor with trepidation.

My new preceptor had spent her entire career in psych. She loved her job, loved the care of psychiatric patients. She set up a rotation because she wanted our entire clinical group to get full exposure to the breadth of psychiatric services offered by this medium-sized community hospital. We would each get to spend shifts on the locked psych floor, observing outpatient group therapy sessions, and in the psych emergency department (ED).

I rotated to the psych ED for the first time on a Friday night. The first couple hours of the shift were very slow. I started talking to the mustachioed guard on duty, who looked as bored as I felt. He told me about his kids, I told him about nursing school. He seemed nice.

When our conversation flagged, I explored the psych ED. It didn't take long—just a short hallway with a bathroom, the social workers' office, and two patient rooms without doors. The majority of the designated psych beds were actually around the corner in the main room of the medical ED—stretchers lined against the wall, without curtains or any

other attempt at privacy. I noticed that from where the guard stood at the corner of the psych hall he had a pretty good view of all the beds. Then again, so did most of the other patients in the medical ED.

Around 7 p.m. traffic started to pick up. First came a teen who wanted to run away from home, then a woman who was afraid she was going to hurt herself. An elderly drunken gentleman whom the nurses greeted by name followed them: they told me in passing he had been a “frequent flier” for many years. As they came in patients were each stripped of their clothes and belongings and given hospital gowns. They all looked discomfited as they surrendered their pants and their cell phones, as if they weren’t sure what wearing jeans had to do with their problems. After a brief interview by a nurse or a social worker patients were assigned a bed and mostly left to their own devices while the staff tried to figure out what to do with them.

Lacking the distraction of their phones or any reading material some of the patients tried to sleep while they were waiting, though the bright fluorescent lights and the exposure to the usual chaos of a medical ED made it difficult. Even so, the elderly drunk man’s snores eventually rumbled in the hallway. The suicidal woman talked to me, then to the aides. The teenager curled into a ball on her bed and cried inconsolably, seemingly not caring who was watching.

The fourth patient of the evening came in by ambulance around 9:15 p.m. A short, skinny man in his late thirties with brown hair and big blue eyes, he ended up in one of the hallway beds. He was, in a word, irate and he wanted everyone to know it. At the top of his voice: *“Excuse me, but why the hell am I here?”* Secretaries and doctors, even other ED patients, turned to stare at the noise. A nurse abandoned her papers and hurried to shush him. *“Sir, your wife called the ambulance because you fell down a flight of stairs, intoxicated, and hit your head.”* Still loudly, he went on, *“I don’t need to be here. I want to go home. Let me go home!”*

The nurse tried to explain that, because he was drunk and had a possible head injury, the hospital could not allow him to leave. The doctors wanted to do a CT scan. He didn’t want one. At some point the

man shouted something about hospitals being the place where people die and it became clear that, in addition to being a belligerent drunk, he was afraid. Perhaps, he was belligerent *because* he was afraid. In any case, he refused to quiet down and made it abundantly clear that he didn’t want to stay on the stretcher. As he got louder, I was asked to stand over by a wall about twenty feet away. I saw the security guard get on his walkie-talkie.

Suddenly there were more security guards gathering, all in police-like blue uniforms, the guard with the mustache leading the huddle. He was the head of hospital security, it turned out. On his way to join up with the other guards he retrieved a bag that contained a variety of restraints, then handed it to me and told me to bring it to him if he called for it. I kept my back to the wall and waited.

There were no further attempts to soothe the man or address his fears. As the nurse walked away, the guards closed in on the drunken man. As they got closer, he tried to stand up. He was really short, probably only 5’3” in his tube socks. The guards yelled at him to lie back down. He didn’t, so the guards grabbed him and threw him back down on the stretcher. They were burly men, but I could see his face through the gaps between their bodies as they pinned him, one to each limb, and the head of security growled at him to *“Lie down and shut up.”*

It was futile to struggle. Futile enough that even this stubborn, frightened, drunk man stopped resisting. Though his eyes were wild, wide, terrified, he agreed to be quiet and stay on the bed. The only presented alternative was to be tied down. The four security men released his limbs and stepped back, but didn’t leave.

It was simply luck that his wife didn’t witness this whole event. She arrived moments later, their seven-day-old baby in tow. His promise of meekness quickly forgotten, in his frustration and fear he began to yell at her, *“How could you do this to me? How could you send me here? You don’t love me or you would never have sent me here!”* The security guards loomed closer once more, so he decreased his volume though not his invective. The short drunk man reduced his wife to tears fairly quickly which seemed perversely to mollify him. She had

humiliated him by forcing him to come to the hospital; he made her regret her decision. He was scared. Now she was too. They were even.

The nurse tried hard to persuade the wife not to do it: “You have the baby to take care of. Are you sure you really want to be responsible for him right now? Are you aware that he might have a closed head injury?” But in the end, he convinced her to sign him out AMA—against medical advice. In the end, the nurse grudgingly gave him back his clothes and cell phone and let her take him home. In the end, they left together, the baby carrier between them.

And in the end, I was left with my back to the wall holding the unopened bag of restraints. The security guards wandered back to their other posts throughout the hospital. The head of security came back and cracked jokes about the patient to me. I didn’t find them funny. I forced myself to sound polite and inquisitive when I asked him where he had gotten his psych training, but I went up to my post-clinical meeting appalled. As new as I was to nursing, somehow I doubted that the treatment of psych patients ought to be so similar to prisoners that no additional training was necessary.

After the other students had rehashed their quiet evening on the locked ward I told the group about the drunken man and the security guards. The other students were similarly horrified but my preceptor wasn’t. If anything, this seemed to sound like a routine Friday night in the psych ED to her. I went on talking, not quite willing to believe her that this was how it was supposed to be. At the very least, I wanted to talk to the head of the psych department, complain to the hospital ombudsman, do something. My preceptor stopped me in my tracks.

In her mellow voice she explained that we were guests at this hospital, that I didn’t understand psych nursing, that I had no right to criticize, that I was just a student. She went on to declare that being a student was “mutually incompatible with activism.” I needed to be quiet, to “keep learning.” She made me feel naïve in my insistence that psych patients deserved to be treated with greater dignity than the scene I had just witnessed.

To my lasting regret, while I chafed at her claims of the student vs. activist mismatch, I did end up keeping quiet. She reported my outrage and my questioning to the director of my program. And though my program director privately agreed with my assessment that something was wrong about what I had witnessed, she asked me not to rock the boat. I finished out my rotation without a peep. But in doing so I feel I betrayed the people in my life who have mental illnesses. I betrayed the belief in human rights, which had led me to healthcare in the first place. And I betrayed the patients who come to that hospital seeking help and compassion and are instead treated like criminals.

I’m now in my final year of school, a mere six months away from sitting the nurse practitioner boards. Since that psych rotation I’ve had ten or twelve more preceptors and hundreds of subsequent patients. I’ve had time to reflect on that experience and I’ve done as my psych preceptor demanded: I’ve kept learning. Sure, some days I still feel like a fraud in my scrubs. But I’ve managed to learn to hear murmurs and give injections and do pelvic exams, learned pathophysiology and pharmacology. I’ve taken ethics classes. I’ve also learned that what I witnessed was wrong—fear and intimidation aren’t the first line strategies in treating psych patients. And I’ve learned that my preceptor was wrong. Nurses are, above all, supposed to be patient advocates. And the mere fact of being a student doesn’t excuse me from that responsibility. I should have listened harder to my initial impulse, should have allowed myself to be guided by my moral compass. I do now.

I will always carry with me the image of that man as he was pinned to the bed as an indelible and invaluable part of my education. His scared, defiant face is my constant reminder to see the humanity and dignity in every patient, even the loud, the scary, the unlikeable. To speak up on their behalf even if my voice shakes. To advocate, even when I feel powerless. To care more. To nurse better.

The Power of Persuasion

G. Bennett Humphrey

A long white coat, the title of doctor, a practiced professional persona and an appointment to the staff of a prestigious university medical center allows the physician to be a persuader of clinical decisions affecting patient management. When this power of persuasion is used to encourage patient compliance with a therapeutic regimen that might be curative for a fatal disease, there is justification for trying to influence the patient to make choices resulting in a positive outcome. But when a physician is asking permission to enter the patient into a research protocol where the primary goal of the study is the hope of advancing knowledge, then much thought needs to be given to the potential abuse of this power of persuasion.

In the 1960s, I found myself having to think about recruiting children into research protocols. I had just finished two years of residency in internal medicine and wanted to pursue a career in academic medicine. My primary interest was in laboratory research. To strengthen my training in research, I had competed for a position as clinical fellow in a western university. The fellowship program was designed to expose young physicians to both clinical and laboratory research. The first year was spent on one of the clinical research wards and the second year in a research laboratory. The program was open to residents from surgery, medicine and pediatrics but because there was a shortage of pediatricians in the program, I was required to work on the children's leukemia ward for one year.

The learning curve was steep during the first few months. Naturally, the faculty in pediatrics and the medical literature gave me a technical education in the use of protocols for therapeutic treatment of leukemia. For example, the first protocol used was

designated as Phase III, and the goal was to try to cure the patient. A remission could be achieved in over 90 percent of children but the disease recurred. The median duration of these remissions in the mid-1960s was one year. A relapse was followed by progressive disease and death in a matter of weeks, but a new drug of unknown efficacy could be administered. This was a Phase II protocol, and while there was a chance of prolonging life for a month or so, the primary goal was the identification of drugs anti-leukemic activity.

The pediatric leukemia ward experience for me as a fellow was unusual. There was more to learn than the treatment of leukemia. To my surprise, the children and their mothers gave me insight into the care of pediatric patients. Each month, the patients were admitted for five days of intravenous chemotherapy. The first day was traumatic with venipunctures, bone marrow aspirations and the establishment of an IV for the daily infusion of drugs. The remaining four days were for social rounds: listening to the children who liked to talk; talking with the ones who liked to listen; putting puzzles together with some toddlers; responding to a request to listen to the heart of a much loved teddy bear; exchanging jokes and riddles; stories about school, the family dog, or a favorite friend; enjoying the banter of the adolescents; and not invading the privacy of a few who didn't like me, the ward or the therapy. These children were sharing their childhood with me and it took couple of months for me to recognize I was bonding with these little patients. I observed and listened to the mothers caring for their children and stood in awe of the resources that they brought to bear on having children with a fatal disease. A feeling of mutual respect and trust developed between these mothers and me. For an internist, these experiences were profound and very different from my experience treating adults.

A professor, an internationally known researcher in the field of leukemia, was in charge of the ward. Formal rounds were conducted on Tuesday mornings when the result of the bone marrow aspirates and the toxicity of the chemotherapy were reviewed. The day-to-day responsibility for

* All names have been changed to protect privacy.

treatment and informing the mothers on the remission status on Mondays was my responsibility. My attending physician made it very clear he was available day, night and on the weekends if I had any questions or needed help.

On a Monday morning during my third month, one of my toddlers, Jeannie Jackson's bone marrow aspirate was full of leukemic cells—a full blown relapse. As I looked at the marrow with a pathologist, I had a sinking feeling in my chest. Jeannie was one of those toddlers who liked to talk, and I enjoyed listening. Normally, the walk from the path lab to the ward took only a few minutes, but this morning, it took forever. I knocked on Jeannie's door, went in and sat down and told Mrs. Jackson about the relapse. She had suspected that Jeannie had relapsed because her daughter's abdomen was bigger, and I had felt an enlarged spleen and liver on examination that morning. My initial task was to listen, to allow Mrs. Jackson to express her feelings and to answer her questions.

Before I could mention the Phase II protocol, she told me that she had discussed this with Jeannie's dad, and that they had decided not to subject Jeannie to any further therapy. Tears rolled down her cheeks. She picked Jeannie up and held her on her lap. "We just want to spend the time at home—no trips to the hospital, no blood tests, IV's, upset stomachs—you know—just be with Jeannie. My parents will stay with us and help—Jeannie's my dad's favorite grandchild."

It all made sense to me so I didn't pursue the subject of additional therapy.

The next morning of formal rounds, my attending was overtly disappointed about the relapse and the fact that the patient was not on the Phase II protocol. When I stated that I thought the mother had good personal reasons for not wanting her daughter treated, the professor asked if I had discussed the response of Jimmy Paul to the Phase II protocol. "That child had a partial response, and received two courses before there was progressive disease. If you'd presented that to Mrs. Jackson, Jeannie might be on the Phase II agent."

"I don't think that would have made a difference, Sir, and Jeannie is after all her daughter," I

said, not out of anger but from my own feelings about Jeannie.

My attending sat back in his chair, took a deep breath, sighed and nodded. "Yes. Yes, of course," he said, and that finished rounds.

After my morning chores, I walked down to a bench beside a lake on campus, sat down and fed a squirrel. This was becoming a habit; it was a place to try to sort through my problems and feelings quietly. I wasn't angry at the attending. He'd been doing clinical research on childhood leukemia for ten years. Through his research and that of others, children were not dying within weeks but now were living over a year and there was a reasonable hope that a small percentage of patients would be cured with the current therapy.

"You know, Humphrey, you've got nine more months of watching children relapse and you're going to be facing this problem of Phase II protocol treatment over and over." I had that sinking feeling in my chest again. I had a professional obligation to encourage a mother to allow us to give a new drug to her child. I had rational reasons for asking, but it occurred to me that mothers had personal reasons for accepting or rejecting Phase II therapy.

I was beginning to feel that the mothers of the leukemia ward were the only ones who could judge what a patient went through when receiving chemotherapy. They knew things that weren't in the toxicity section of the protocol, knew things that weren't in pediatric or internal medicine textbooks.

I thought back to Jimmy Paul who had been admitted for terminal care in July, my first month on the children's ward. The decisions to start the Phase II agent had been made in April and Mrs. Paul and I never discussed why she'd agreed to this course of therapy. Jimmy was a memorable child. He liked puzzles but didn't want me to help. He'd spill food off his spoon, but he wouldn't let his mother feed him. Like all children on the ward, he was unique and likable.

Call Mrs. Paul, I thought. Ask her why she wanted her son to receive the new drug, what was her experience and did she have any regrets.

It wasn't my habit to outline what I wanted to cover in interviewing a patient or in this case a

mother, but I thought I had better think ahead about my conversation with Mrs. Paul. I wouldn't be able to observe facial expression or body language to judge if Mrs. Paul was uncomfortable talking to me about her time on the leukemia ward. More importantly, I had never asked a patient, or in this case a mother, for help on how to do my job better.

Mrs. Paul answered the phone. She said she was still adjusting to Jimmy's death, but she didn't mind my calling. The conversation proceeded without difficulty. Her answer to why she agreed to the Phase II protocol was, "I didn't want any 'what ifs' haunting me." She went on to say she now knew that they had tried and it didn't work, but that Jimmy had lived a little longer, four months longer. She felt the toxicity was unpleasant but reminded me, "Jimmy was a tough little boy."

I told her how I had noted her respect and pride in her son and that Jimmy was indeed a tough little boy.

Mrs. Paul's final remark was, "You know, Doctor, when your child is four years old, four months is a lot of time."

Wow, I thought. Mrs. Paul's personal reasons for accepting were just as powerful as Mrs. Jackson's personal reasons for rejecting Phase II therapy. The discussion of Phase II treatment would remain difficult but now I could present the scientific, rational reasons for why we needed new and better drugs, and couple that with the personal reason of two mothers, one choosing to accept and the other refusing the drug trial.

During the remaining nine months, I would continue to learn about pediatrics and the treatment of leukemia from my professor and the medical literature. From mothers and children, I'd learn other things. As these nine months rolled by, I used my power of persuasion to encourage mothers to be compliant with Phase III therapy and tried never to abuse that power when discussing phase II protocol research.

This would be the most profound year of my life as a physician. I came to respect the importance of clinical research and went on to participate in the clinical trials that were being done.

I left the field of internal medicine, trained in pediatrics and became an oncologist. Any physician working in a field of chronic disease, life-threatening disease is going to have to deal with moral distress or ethical issues. To try to resolve such issues, the physician can turn to professional colleagues, psychologists and the patients themselves. Pediatricians are lucky. We have an additional resource. They're called mothers.



Carmen Miranda

Jessica Les

Carmen Miranda, she called herself today. She suffered from decades of schizoaffective disorder and now more recently, end-stage renal disease from uncontrolled diabetes. I first met Carmen two weeks prior when she had been brought to the hospital on a 72 hour psychiatric hold for self-harm. She failed to go to dialysis for a week, an act that would kill her if allowed to continue. Now she was here again, for the same reason.

Everyone of competent mind has the right to refuse medical treatment. Unfortunately, Carmen's mind was not currently grounded in reality. So against her will, our family medicine team admitted her to the hospital and arranged for dialysis early the next morning. None of us liked doing this. Fortunately, when the time came for the dialysis tech to insert the dialysis catheter into her shunt, Carmen agreed peacefully. After her dialysis, we had no right to keep her in the hospital because her life was no longer in danger, at least until the next week. We discharged her to home. However the question remained, what about next time?

To navigate this ethical gray zone, we called an ethics committee meeting. An ethicist, nurses, hospital social workers, the inpatient family medicine resident team, and most importantly, two people who knew her very well—her caseworker and long-term psychiatrist—discussed her case for an

hour. Our medicine team learned that in her last period of clarity two months prior, Carmen made contradictory statements regarding her wishes. Carmen told her caseworker she was tired of dialysis and being sick and stated it was time to let herself go. During the same lucid week she told her psychiatrist that she was grateful she had been forced to complete dialysis against her wishes after a run of non-adherence while suffering psychosis a couple of months prior. Now months later she was in a downward spiral, exacerbated by the deterioration of her mentally ill husband. If she missed a dialysis treatment here and there, it was okay, but when she went on a run missing several treatments, it was slow suicide.

The ethics meeting concluded that Carmen needed to complete an advanced directive and select a power of attorney other than her gravely incompetent husband as soon as she was deemed competent. If she did not become lucid again, her psychiatric team should apply for conservatorship, a legally appointed person who serves as guardian for a gravely disabled mentally ill person. However, conservatorship would take months. In the interim, the ethics committee ruled that our medicine team would continue to provide lifesaving treatment for her, against her wishes if necessary.

The ethics meeting adjourned but our medicine team remained in a gray area. To what length should we go to treat her? If she continued to refuse dialysis would we hold her in the hospital until she became sufficiently docile by inevitable uremia that we could peacefully dialyze her? *Possibly*. Would we go so far as to put her under anesthesia to complete her dialysis? *Personally, I hoped not*.

Just three days after the ethics committee meeting, her caseworker found Carmen yelling nonsensical phrases through the front door of her home while her husband held the door shut with his beer belly and good shoulder. After gaining entry later in the day, Carmen's caseworker found their mutual medication collection strewn in the bathtub and no food in the house. He placed Carmen on a psychiatric hold and transported her to the hospital. The emergency department paged me when Carmen arrived. I braced myself for the possibilities that lay

ahead. When I reached Carmen, she was sitting in a room reserved for psychiatric patients and under watch by a friendly police officer accustomed to these situations.

"Hi, Carmen," I said, one step into her room. She sat on the edge of the gurney, wrapped in three blankets.

"Cold," she said.

The police officer spoke from behind my shoulder, "She has been requesting cup after cup of ice water, she won't take anything else."

"Let's get you more comfortable." I returned with a warm blanket and draped it over her shoulders. Carmen stared straight ahead. Sitting on the gurney next to her, I saw her hair was clumped in strands and dirt had collected beneath her long finger nails. She wore an amulet around her neck. I wish I knew what she wanted for herself.

"Carmen, do you know why you're here?" I asked, holding my breath.

"It snows in Alaska. And in China," she said to no one in particular.

"Yes, it does snow there. But you are here to get dialysis." My heart ached for her.

"My kidneys hurt. Time for dialysis. Snow in Alaska."

"Good," I responded, carefully letting out my own breath.

I was relieved. At this moment, it felt as if we were doing the right thing for Carmen. I was grateful she appeared willing to accept dialysis and that I wouldn't have to visit the decision of waiting for uremia versus considering anesthesia. Another crisis averted, at least for today, I thought to myself.

I was wrong. A different kind of crisis unfolded that I did not anticipate.

When I walked out of Carmen's room, several distraught hospital staff pulled me aside and questioned why I was admitting her for treatment against her will, again. I explained Carmen's recent conflicting statements and the ethics committee's planned course of action, however unsatisfying, until she was stable enough to communicate her true wishes. I repeated this conversation with other distressed hospital staff involved in her care eleven more times that evening.

I was a tired resident and aggravated to repeat this conversation again and again while other patients awaited care. I also had my own reservations about the ethics committee decision, which I could not share. As a resident I felt that in addition to learning medicine and providing patient care, I also needed to be a diplomat. The emergency room physicians want you to swiftly get the patients out of their emergency room into a hospital bed upstairs. Faculty expect critical thinking and a broad differential diagnosis for every patient both for your own learning and to provide exceptional patient care. Nursing staff, already overstretched, want simplified familiar orders and as much completed in the emergency department as possible prior to the patient arriving on the floor. The resident is the learning diplomat coordinating these opposing desires. Every day in the hospital I felt a pull from these contrary forces, but the ethics committee decision and the response of the hospital staff pulled too far.

Driving home from that hospital call, the night's events replayed themselves in my mind. I tried to bring closure by telling myself that Carmen and all of us involved in her care had to take this journey one day at a time, hoping that Carmen's next period of clarity was around the bend and that none of us got hurt along the way, because neither we, nor Carmen, had much choice in the matter.

But Carmen and her story wouldn't let go of me. There was something unfinished that I needed to resolve. So I turned to writing, my old tool for processing and understanding. Writing first became my go-to for sorting complex and trying medical experiences when I had breast cancer in medical school. Whether journaling or writing for publication, crafting narrative often brought clarity, power and peace to otherwise disempowering experiences. I continued to write in residency to find meaning in patient suffering, moral dilemmas and medical training itself. I felt compelled to write "Carmen's" story because I remained troubled months later, even after debriefing with supportive faculty and senior residents.

As I wrote the story I instantly felt pulled back to the draining conversations with hospital staff

repetitiously explaining the ethics committee decision. I realized that the conversations I had were among the most important acts of my day. Because without the whole story explaining Carmen's contradictory wishes to date, the ethics committee ruling was empty and placed hospital staff in jeopardy of emotional harm by the care they were obligated to provide Carmen against their own wishes. Although the ethics committee ruling did not comfort staff, quoting Carmen's own contradictory statements during her last period of lucidity provided a salve for those caring for her.

As I wrote I recalled the faces of the people providing care for Carmen. Their furrowed brows, clenched jaws and even tears welling up. I wondered how often we consider the emotional repercussions of people administering involuntary care to patients, even if deemed "ethical?" Health care is not delivered in a vacuum. Precisely what makes health care human, the one-on-one contact with our patients, makes it dehumanizing if we doubt the validity of the care we provide. Although patients must come first, ethics committees should consider the impact of their rulings on hospital staff and the methods with which they communicate their verdicts. More than the patient can get hurt when navigating an ethical grey zone with a patient.

I finished the story, edited it, and shared it with peers and mentors but surprisingly I did not find the peace I anticipated. I let the story sit for a year and then read it again after residency ended hoping to find closure and release.

That is when my writing yielded an unexpected reward. I realized that the ethics committee ruling itself was not necessarily wrong but rather the method with which it was deployed set all of us up for failure and distress. It was not easy for myself, nursing and other hospital staff to care for Carmen. However, what distinguished difficult from emotionally damaging was simply the full back story of Carmen's contradictory statements during her last period of lucidity. Had all staff involved in her care been privy to this information revealed during the ethics committee meeting, I would not have been put in the position of defending the ethics committee's decision while also trying to carry on my job

as a resident physician—learning medicine, navigating patient care, and making clinical decisions under stress and with speed. Nor would the nurses, dialysis technician and others involved in her care have suffered the unnecessary angst of providing medical care they morally disagreed with before extracting the full back story from me.

A carefully arrived upon ethics committee decision is not sufficient to provide just care for patients. The details behind this decision must be summarized and fairly disclosed to hospital staff providing direct patient care and not left to the resident physician to communicate with those equally distressed as she. This was a missed opportunity for effective hospital communication that resulted in unnecessary anguish. Since then I have sought to close this communication gap.

I contacted the bioethics committee and learned that they were already re-vamping the hospital bioethics committee process including communication of the committee's recommendations. My inquiry came at the right time.

A representative of the bioethics committee said, "Yes, as a part of this re-design the ethics committee consult note will be immediately available in the chart."

I pushed further, "That is a great step, but for the communication gap to close a synopsis of the committee discussion leading up to the patient care decision must also be available in the patient chart for every admission. Is this possible?"

"Yes, we can make that happen. I think that would be very much in line with our goal."

Finally, my heart lightened.

In this instance, the process of writing itself did not provide the salve I needed to completely move forward from Carmen's story, but rather it provided the clarity to see my next steps. I needed to prevent this from happening to future residents and hospital staff. Only after working with the ethics committee to come up with a solution to close the communication gap in the future did I find the peace I sought when I began writing and now I can say this story had an end.



When Moral Uncertainty Becomes Moral Distress

Cheryl Mack

This narrative is really for me about a process of discovery, it begins with a discrete event of moral distress, but it certainly does not stop there. It really represents for me a transformative moment, radically altering my career path, and changing how I define medical wisdom and judgment. The day it occurred I arrived at work to find my list had been altered rather significantly; the first case in my room was to be an organ donor, which in and of itself was not too unusual. What made this case very different though, quite beyond the experience of the team, was that we were dealing with a maternal case of brain death with a still viable, but extremely premature fetus. Questions arose in my mind. This fetus was too young to be delivered now, but had the possibility of trying to maintain the pregnancy been reasonably explored? Would that have been an option this mom would have chosen? Had the father been offered the opportunity to consider this? All would seem to be important questions for the team to consider. What really struck me that morning was despite the unusual circumstances of the case, the complexity of the case, the lack of expertise with regards to the uncertain clinical and ethical dimensions of the case, there had been no "... heads up, just thought you should know that..." phone call the day before. The head of the intensive care unit had not been informed either, so I was certainly not alone in being out of the information loop. I should make it clear that the nature of organ donation is such that these cases takes hours to organize, to find recipients, to mobilize the necessary teams for harvesting, so organ donation is not an emergent case. Given this lag time there was certainly time to not only inform the team, but given the unusual circumstances, time to initiate a more comprehensive consultation process, a consultation process that could have ensured that the ethical and clinical dimensions of the case had been reasonably explored. Of course by the time I had arrived that morning the teams were on their way, there now was an urgency to get the donor to the operating room.

I felt unease about the case, and questioned the nature of the consent provided by the family. Were they made aware that choices had to be made? Did they understand that there was a paucity of evidence regarding these choices and that in these circumstances they need to make a decision that best reflects the wishes and values of the patient? My questions regarding the consent went unanswered so I asked for an ethics consult (I was surprised that this had not been done already, given the complexity of the case). This request was unfortunately denied, the explanation being that the family had already signed a consent. Maybe I failed to be clear in my request, that it was the circumstances and informed nature of the consent that I was questioning. Here, I admit I was beyond my experience, I had never had reason to question a signed consent form before, and maybe it was this lack of experience that impacted the request and hence led to the denial. Maybe the ethics team was satisfied with the consent, but they did not communicate why they were satisfied and so I felt that I was still left with reason to doubt the moral support for that document.

I am prepared to deal with moral uncertainty in the tertiary and often quaternary care nature of my practice. We often are called upon to make clinical decisions without all the relevant information in terms of risk and benefit. What makes moral uncertainty something that we can come to terms with is the knowledge that the patients can at some level understand this uncertainty and trust in the decision-making and advice of the team (and team, in the face of uncertainty and complexity ought to be broadly construed). There needs to be an acknowledgement of the necessary time and space for adequate reflection for often these decisions are irreversible and we need to ensure that options are fully explored and values respected. The decision making in this instance felt rushed and failed to solicit the advice of the broader team. The result was that many clinicians that day felt morally distressed. What was my reaction to that moral distress? It best can be described as isolation, although I was active member of the care team to be involved, I felt I was relegated to being a quiet bystander, a technician expected to provide the skills, but not the critical reflection, which I still feel makes us physicians. I

wasn't the only healthcare worker on the team that day that felt distress, but the circumstances that day made me feel rather alone. A few of us removed ourselves from the care team that day. My decision to do so stemmed from my uncertainty but also from my belief that my actual distress would impact my ability to provide care, my feelings of isolation from the team impede communication in some critical fashion. My actions certainly registered very publicly my distress and some probably felt it was unprofessional, but I believe going forward to provide care under such circumstances would have been truly unprofessional.

So feeling like I actually did nothing that day for the patient, I went home with a different type of uncertainty, uncertainty about my future in clinical medicine; whether I actually was a good fit for the career I had chosen. I felt wholly unprepared for dealing with either the situation as it arose and unprepared for the conflict between the personal and the professional within me. After being informed that no interdepartmental rounds would be considered; the sense of isolation from the hospital leadership also grew. There were no formal reprimands but there was also no acknowledgment of any possible existence of moral uncertainty. There was no avenue provided to clear the air and engage the staff in a process that allowed us to learn from this experience, to hopefully do better in the future, to gain collective wisdom.

It was moral uncertainty combined with an urgency that was created, that we created, rather than an urgency that was uncontrollably thrust upon the team. A perfect storm of uncertainty really, a rare situation, with conflicting moral obligations and an urgency that led to a decision making trajectory that failed to fully explore the implications of these conflicting obligations. The decision that day may in fact have been the correct one. What concerned me was the certainty that effectively shut down ethical reflection and may have limited the ability of the family to consider the values of the patient and how that patient might have defined best interests and perceived moral obligations. Considerations that might have impacted the decision making that day. It is precisely when uncertainty arises that these considerations carry even more

weight and can provide critical guidance. I worried that day that the created urgency did not provide an opportunity for the family involved to take the time to reflect on these considerations. With the appropriate time, the family may have still made the same decision. I felt the process did not serve or acknowledge moral uncertainty that day. I was left with questions, with distress that the uncertainty wasn't fully disclosed and best interests perhaps not served.

Moral uncertainty is common, but it is the evolution of this to moral distress that you have asked me to discuss. Moral uncertainty becomes distress when you think that you are alone in this feeling, when avenues for open discussion either do not exist or the questions that are bothering you are not given serious consideration by either your colleagues or the hospital administration. It becomes moral distress if there is no forum to discuss, to debate and perhaps even more important, to give pause. It does seem sometimes that in our rush to "do" that we create an environment that stifles the healthy expression of uncertainty. This rush "to do" must sometimes take precedence, there are times when it is most reasonable to in fact intervene in the face of much uncertainty, acknowledging and accepting that the "we ought not have" might become apparent later, that with more facts or more discussion of best interests we conclude we ought to change the trajectory of care or withdraw altogether. This is the reality of clinical medicine. There is often an urgency that directs us to get a job done and pause for more critical thought later. Again these instances of moral uncertainty do not necessarily evolve into distress.

Moral distress occurs when we fabricate urgency, when we create a situation that brings about an unnecessary urgency and in doing so we shut down the normative dimension of our decision-making. This is where we risk failing our patients and failing ourselves. This is where we really lose sight of the goals of medicine, which are to provide the best and lacking the necessary knowledge to help inform what is actually best, to provide the most reasonable care for the patient in front of us. Providing the time and space for ethical dialogue not only serves

to alleviate a lot of moral distress, but the richness of this dialogue can, I have learned, not only serve to alleviate a lot of moral distress, but the richness of this dialogue can create an environment that is both patient and caregiver focused. An environment that invites questioning, that enables expression of uncertainty is an environment that also facilitates critical reasoning and true learning. It is an environment that fosters clinical wisdom.

Of course what I have just written is the result of a process of discovery and learning that I necessarily embarked upon. I have come to make some sense of and make peace with moral uncertainty. I have become more confident in admitting that true clinical wisdom is a state that we reach when we admit what we do not know. I have gained some confidence and ability to have conversations regarding uncertainty with my patients, some of this I have gleaned from wise mentors, but most I have gained from the best teaching a clinician can ever ask for, from my patients and their families. I am however, still an apprentice in these types of conversations. However, only by continually engaging in honest conversations about uncertainty do you have an opportunity to gain the tools and language to do so with a facility that enriches uncertainty. A lot of bumbling about, struggling to find the correct words combined with a lot of understanding from patients and eventually you achieve a level of ease with this type of disclosure, a disclosure that ought to engender trust and help build a decision making process that is shared and moral; mutually respectful of patients and their professional caregivers

There is no escaping the fact that I could have done better that day; better for the patient, better for my colleagues and better for myself. The questions I continued to ask myself were what would I have changed if I could, what could have been done to do better, and what could I do to better prepare myself for dealing with such a case in the future? Well past experiences with feelings of being inadequate were always assuaged by practice and learning, this approach had always worked for me so that is how I dealt with the aftermath of this event. I decided to gain at least competence and

hopefully expertise with regards to the nature and normative dimensions of clinical uncertainty. I undertook graduate studies in healthcare law, moral philosophy and philosophy of medicine. This radical change in my career is the direct result of this case. I still practice tertiary care, and what often seems quaternary care, clinical medicine, but I also pursue this academic interest. I now spend my nonclinical time in clinical ethics, consultations and education, it is my way, at least I hope, to provide venues for open discussion regarding clinical and moral uncertainty. This is for me a positive aftermath of moral distress.

So in a crazy way I am thankful for that event, where it has taken me. I believe many, if not all of us in medicine will have encounters with moral distress, many more than once, and at very different levels and kinds of experience. This event was isolating and made me question not only my place in clinical medicine, but also caused me to question the goals of medicine. The journey it led me on has been one of clinical and personal discovery. I believe I am a better physician and a better colleague, hopefully also a better person because of it. I approach the grayness of medicine with much more respect and humility, I search for what is reasonable, realizing that perfect and best can lead us astray and can cause inadvertent harms. I love what I do, but I love it more now because I know it is right to question what I do.



“Can They Do This?” Dealing with Moral Distress after Third-Party Termination of the Doctor–Patient Relationship

Susan McCammon

Not so long ago, a storm badly damaged the tertiary care hospital in which I practice surgical oncology. In the aftermath of the storm, the institution determined it was no longer able to provide unreimbursed cancer care, and

many of my patients were terminated by a form letter from the hospital. The helplessness and outrage that I experienced when I was first handed one of these letters, crumpled from the damp fist of one of my patients, was immense, and frightening in its unfamiliarity: “Can they *do* this?” I asked repeatedly, ascending a hierarchy of authority, which was increasingly reticent and then elusive. In short, the answer was “yes.”

While this decision was made by the administration, its enactment was delegated to the physicians. Thus, not only were the physicians not involved in the decision to terminate their patients, they shouldered the burden of telling their patients that they would no longer be treated. The reason given—storm devastation—was contradicted by the orderly flow of insured patients in and out of unaffected clinics and hospitals.

In those months, when the operating rooms were closed, I took to the road and learned about hospice and palliative care medicine on the ground. I drove from city to smaller city to the devastated countryside, locating my patients and providing all the care that I could with only my hands and mind and heart. I struggled with the limitations of the health care system and worked to rebuild a sustainable infrastructure at my own institution, all while trying to come to terms with bioethicist Haavi Morreim’s (1995) caution that “. . . it is not the physician who owes the resources at all. He cannot owe what others own and control, because moral obligations can only be assigned to those capable of fulfilling them” (p. 87).

In considering my experience of moral distress over this period of time, I have reflected on the different connotations of the word, “practice.” I grappled with the philosophical terms “practice,” “praxis,” and “phronesis,” and I questioned their relevance to the word, as used in my professional life. However, in struggling to understand my moral obligations after the storm, when I was learning to do what I could, even when I couldn’t do what I felt like I should, I reconsidered. The elements of immersion, repetition, particularity, and utility that pervade this language of philosophers and artists turned out to be what preserved my ability

to practice medicine in a space holding only patient and practitioner.

Many of the patients that I take care of are very poor. Many more are working but uninsured. This is a result of both their risk factors and the demographics and resources in my geographic catchment area. Their access to care was disrupted after a natural disaster and concerted efforts to reestablish it have not succeeded. Since then, I have learned how to tell people that they will die of cancer because they don't have enough money. This is not a skill I was taught in medical school. I can talk about death, imminent or not, feared or anticipated. I can talk about unresectable tumors, treatments that have more risk than benefit (or no benefit at all), suffering beyond what has yet been experienced or imagined, helplessness, futility and grief. I could be neither surgeon nor oncologist without some facility with these. But I was unprepared for this move from medical to economic "can't," the nexus where an institutional "won't" becomes a personal "can't."

I should say here that I was not blind to the expense and technological hype of the American medico-industrial complex or our systematic marginalization of public health or the ever-present cries for health care reform. I understood that I was a steward and that I served both the individual and the society and had at my disposal what I was told were limited resources. These values, however, were only just being incorporated into the training of medical professionals; certainly they played no role in my own education. Morreim's (1995) conclusion that "the physician owes his patient what is his to give" (p. 2) seemed to me prescient but distant, and I was left in an arena in which I had to make moral choices, often with little or no professional guidance.

When I approached my mentors for advice, I got a single response with a multitude of plans. They all said, "You need to get out of that situation. It is untenable." Their exit strategies were diverse. Some were well intentioned:

The administrative spin: You can't help these patients, but you can work within the system to reform the indigent care policies so that you can help future patients.

The public health spin: You can't solve this problem on an individual level; the only way to help this population is to . . . reform health care, tax tobacco, focus on prevention.

The biomedical research spin: It's a waste of your intellectual resources to treat the same thing over and over again; what you need to do is get into a laboratory and cure something. Then think of the patients you can save!

Some were well intentioned, but less noble:

Physicians shouldn't have to deal with this. You need to separate the financial screening from the clinical arena, so that you are only seeing the people who are accepted for care. It's too hard on you otherwise. You will burn out.

You can't practice "good medicine" if you have to adjust your recommendations based on a patient's coverage or ability to pay. There is only one gold standard of care. You will get sued.

Surgeons cut to cure. Once that is not possible, your job is done. If they have money send them for palliative chemo, if they don't, send them to hospice. You will waste your time.

These two moves—escape or hide—left behind the issue of what to do with the people in the waiting room, gripping their letters, and the ones who couldn't even make it that far. And there were a lot of them.

My practice of surgical oncology has changed irrevocably. While I have worked hard on the committees to reestablish institutional resources for our future underinsured patients, I continue to go to free clinics and homes and witness and care for my current patients, one person after another, even if that care is an examination and a diagnosis and an explanation and a foregone conclusion that now I can see from across the hall. Like scales on the piano, or *asanas* on the Yoga mat, or any of a variety of internal goods pursued by practitioners of all kinds, each repetition is worth doing, in and of itself, and has the potential to transform both the patient and the practitioner. What I continue to struggle with is the importance of continuing to practice in the absence of transformation, and owning the risk of invisible mitigation of broken systems.

I am still not sure if I do more harm than good, if how I manage patients is right or wrong. I can

articulate my values, and live as if they were virtues. I believe that sometimes one must do one's duty regardless of the consequences, and I believe that some consequences are worth achieving at almost any cost. Has this moral life brought me *eudemonia*? Not really. It is more like a lifeline, the b-flat-minor scale, *Chandra Namaskara*, the rosary, the laundry, the value of ritual and witness, repetition and transformation.

Those months after the storm were for me, a little like being abducted into the underworld of Greek mythology—Persephone tricked by Hades into eating the pomegranate seeds that would ensure her perpetual return. This was a realm where people dealt with the practicalities of dying and death mostly on their own. Even when the hospital reopened and I returned to operating room, I found myself drawn back again and again to this place of patients and families who no longer had access to the bright institutional resources of modern medicine.

I am a newly board-certified hospice and palliative care medicine physician, a role I never anticipated, and one I incorporate into my surgical practice. I work with people along the full spectrum of living and dying and suffering and relief. I no longer conceive of my work as an alternation of fertile and fallow, colored by the residual frustration and impotence of "losing" my patients. But this is not a story of triumph and renewed strength. Much of what I still feel is resignation and despair. I still start awake at night, in a cold sweat, sure that I have overlooked a pathway to care, that what I am witnessing in the health care system is deeply wrong, that surely this is not meant to be, that if the powers that be only knew. . . . Referring to initiatives to bring cancer care to the developing world, oncologist Lawrence Shulman (2012) has written in this journal that "[t]reatment of curable cancers should be considered on par with the right to clean water, adequate nutrition, treatment for infectious disease, and access to maternal and child healthcare services," and he quotes Princess Dina Mired in the same article as saying "that the opportunity to survive cancer should not be an accident of geography. In cases where we already have effective and inexpensive tools to cure cancer, these treatments should

be considered a basic human right, a life-saving medical service (p. E10)." Sometimes I startle awake in meetings at richly polished conference tables and wonder what really constitutes a "resource-poor setting" and if these people could come help me.

* * *

How do I live now? Very simply, one (inter)action at a time, with the people in front of me. I do what I can and I share regret for what I am unable to do. Then I do it again, and again, and again. Is this the way I should behave? Is it the right thing to do? If I added up all the nominal co-pays and the costs associated with emergent tracheostomies and gastrostomies and pain crises, as well as my professional time and overhead, I imagine someone could be treated curatively. But how many people would have their terminal condition communicated to them by form letter? Is it not worth the time and effort and overhead to explain it in person and be with the family who will go home with this news?

There are so many grander ideals for improving the health of our people. Should I not be pouring my energy into those? Fighting for reform (from health care to campaign contributions) on a national level, insisting on accountability or at least consistency from my colleagues, advocating tirelessly for resources, access, money . . . these hold the promise of greater good for greater numbers. But I don't do those things. I hold hands and weep with patients and go home so very tired. I feel guilty for not taking up arms. I know that what I do graces these patients, but it is so small, and it is so clearly defined as all that I *can* do.

In my waking hours, I still struggle with the roles of advocate and witness. Even now I am in the process of advocating for an unpopular treatment plan for an unappealing patient. He has advanced cancer. I have watched it advance with him on a weekly basis, intervening with "emergency procedures" that represent the least effort we can expend to stabilize him and discharge him. He is uninsured and he is not wealthy. He and his family and I and my staff are navigating the obstacle course of modern medicine, and his cancer advances.

I am quieter now, more bitter; I often feel like a failure. I have gained by being able to empathize

with my patients in terms of helplessness and the temptation of destructive coping mechanisms. My residents look to me for heroism and I am only able to offer perseverance; my department wants me to repopulate my surgical practice with insured patients while I turn away the uninsured; and patients still come to me for rescue and are outraged when I cannot save them. I open their airways, and I give them access to nutrition and narcotics, and I grieve the fact that this is their county, their state, their country, their accident of geography. It is the most I can do. It is the least we can do.

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Moral Distress: The Face of Workplace Bullying

John S. Murray

After a 28-year long distinguished military career I accepted a research position in a tertiary academic health science center, which I considered to be my dream job following retirement. Initially I was to be responsible for one department. A second was added because of my expertise with disaster preparedness. Following my orientation, I immersed myself into my new roles recognizing that there was much to be done to achieve the goal of getting both departmental

research programs up to par with the rest of the organization. In a short time, I began to recognize one of my bosses was going to be challenging to work with.

She expected that her name be included on all grant proposals and manuscripts despite making no substantial intellectual contributions to either. Additionally, she wanted unwarranted control over all research and scholarship activities I was engaged in with staff despite having no research experience. Even meeting with her to discuss my plans for the direction of research in this department, my efforts were met with argumentative and condescending behavior. She would agree to discuss my plans. When I showed up for meetings in her office she would get angry with me oftentimes for situations, which she herself created. I continued to move forward with my work feeling that how I had conducted research and scholarly work in the past, with integrity and uncompromising ethical standards, was going to be threatened. This created great moral stress for me. I felt overwhelmed, powerless and frustrated as a result of the uncertainty as to whether or not I could fulfill my responsibilities while still meeting moral obligations.

Over time, my moral compass prevented me from deviating from the principles, which helped me to build a long-standing stellar reputation as a leader in the field of pediatric nursing. However, this came with a cost. Working for this particular boss was like being on an emotional rollercoaster. One day I would feel like she was pleased with my work, but the next day my efforts could be met with anger, demeaning and dismissive behaviors. Once she praised me in front of staff for the "great" work I was doing with the evidence-based practice initiative nurse leaders. The following day she reprimanded me for not working closely with this group. She was extremely well versed at singing my praises in front of staff. Behind her closed office door was a very different experience.

I confided in some colleagues in this department how I was being treated. I quickly learned that all staff were treated in this manner by this one individual. They shared that condescending language and fear and intimidation were the norm. When

* All names and titles have been removed and feminine pronouns have been used in all cases to help de-identify the individuals in this story.

I asked them why no one had the awareness or courage to say this treatment was not right, they quickly shared with me that staff were deterred from speaking up for fear of greater bullying behaviors. Sadly, while everyone knew what was the right thing to do, institutional constraints made it nearly impossible to pursue the right course of action. It was readily apparent these nurses were missing advocacy. At that point, I decided it was important to seek a remedy to this problem recognizing it would be no easy task.

Progressively, my work environment with this particular boss became intolerable. Despite working relentlessly to develop a research program, unwarranted criticism, unjustified blame, exclusion, isolation, unreasonable demands and denied opportunities persisted. By this time, I was suffering from nightmares, headaches, fear, anxiety, depression, difficulty concentrating, and problems with self-esteem. I felt like my professional competence and reputation was being unjustifiably denigrated by this one individual.

In the past, I confided in trusted organizational leaders for guidance when faced with difficult situations. As such, I approached my other boss and shared what was happening. She was deeply concerned. She encouraged me to seek guidance from a safe and confidential environment where staff members can share concerns and receive assistance with how to handle these apprehensions. I had used a program like this in the past when dealing with moral distress. This experience was very helpful. In fact, I returned on multiple occasions when my work situation was overwhelmingly stressful. At one point, the provider I saw was concerned that the unhealthy workplace in this one department was causing post-traumatic stress disorder (PTSD) symptoms. During this same time, I was working with a senior hospital administrator who my boss reported to. Initially she was receptive to my concerns. She listened but asked me to not go to human resources (HR) permitting her to address my worries. Out of respect for her, I did so. Unfortunately, my trust in her was eroded over time as she found every excuse possible to not hold my boss accountable for her actions. I eventually learned that these

individuals were friends and lost confidence that something would be done.

After giving the senior hospital administrator several months to address my concerns, when nothing happened I finally went to HR to seek their help. The representative I met with, while concerned with my complaint, was not surprised. She acknowledged the long-standing history of similar concerns with my boss. The representative asked why I waited so long to contact HR. I shared that the senior hospital administrator asked me not to discuss this with HR. However, at this time I needed to report to HR what I had been experiencing. She acknowledged that action was immediately needed.

When the senior hospital administrator found out I had gone to HR, she responded with a vengeance. While my work situation continued to worsen, she dragged her feet to address the problem. One day she called me to her office to tell me she was not happy I spoke up about this problem. I shared with her that the situation was not healthy causing me ongoing physical, psychological and social distress. In the days to follow, it was very difficult for me to make sense of all this. In fact, one colleague told me that I "should have never opened my mouth about the problem."

Another two months passed and nothing was even remotely done to address my concerns. One day out of the blue, another senior hospital administrator requested that I meet with her with no notice. When I reached her office, she angrily told me she was not happy with the way I handled my workplace concern. She disciplined me for doing what I believed was right by telling me to go home for the week and think about "whether or not I felt I fit within the organization." I was shocked to say the least. I went to HR to speak with them about what was happening and was told she can do whatever she wanted.

That week was emotionally traumatic for me. I felt very depressed, isolated and could not sleep. My family worried about me to the point where they asked the local fire department to stop by and do a wellness check. Friends and colleagues tried to be supportive. However, I was emotionally numb and found it very difficult to speak with anyone

about what I was going through. It was pure hell. As best I could, I made a list of all the things I had accomplished within the short time-frame I was employed at this organization. There was no doubt in my mind that I loved working there except for the hostile work environment in the one department.

I returned to work the following Monday and was asked to meet with the hospital administrator the following day. To say that I was anxious would be an understatement. Upon entering her office, she sat off at a distance at her computer. I sat at the conference table. She asked if I had thought about her question regarding whether or not I fit in. I responded that I loved my job but found it unendurable to work for my one boss. She demanded that I resign. Not knowing her reasoning, I asked for additional information regarding her concerns. She told me she did not have time. When I told her I could not resign, she angrily told me that I would be terminated. It was very clear to me at that point that she was not interested in my concerns regarding workplace bullying and the moral distress it caused me and others. I was told to go to HR. Before doing so, I met with my other boss who was devastated by what was happening. When I finally got to HR, I was told to “just make this easy on yourself and resign. You have a great CV and can find a job anywhere.” I declined to do so.

Over the next couple of days, the reality of what happened took a huge toll on my physical and psychological well-being. I felt numb, removed from my body, depressed, and anxious. It was clear that I needed help. I called a wonderful colleague of mine, who worked at the same organization, asking her to help me. She unhesitatingly agreed to help me seek care. In the meantime, I called one of my sisters to tell her what was going on. She took the day off from work and ended up being the one to take me for urgent care. After several hours in urgent care, I was told that I had the hallmark symptoms of acute PTSD. In order to avoid hospitalization, I agreed to spend the next week with family and attend weekly follow-up appointments. During this time, I received unrelenting calls from HR asking me to resign. One day on the way to a medical appointment, I received a call from HR and asked the person to stop harassing me during a time when

I needed to focus on my well-being. In the ensuing days, I was still bombarded with calls from HR. So that I could focus on myself, I obtained legal counsel so my employer would stop intimidating me. In the end, I was terminated without cause.

Several months have passed since this event. It's been a tumultuous journey to say the least. If not for the incredible support from my family, friends and many colleagues at the institution where I was employed, I wonder where I would be. Several months of therapy have helped me to begin to regain my sense of worth. While this experience has been horrifying to go through, it has made me a stronger person. I do not regret speaking up about the awful work environment and moral distress I and others experienced despite what I have been through. While I doubt the leadership cares, or has considered the impact this experience has had on me as just one employee, I know that countless employees have taken note and hope they will stand up for what is right. As I have learned the hard way, no job is important enough to endure workplace bullying and moral distress.

It's a sad indictment that my experience is not an uncommon one in health care. Moral distress is ignored in health care. From my perspective, it seems to always happen to the good, conscientious and hard-working people. Undoubtedly, a system change is needed to address any situation, which creates moral distress. However, a very strong wall of silence exists which prevents professionals for doing what is right—speaking up without fear of retaliation.

I have always been someone who has stood up for what I believe is right even when risk is involved. While I hope the health care industry gets a better sense for how widespread workplace bullying and moral distress are, I have chosen to seek an alternative route to attempt to address this escalating problem. I've determined that path should be through legal education. I have a particular interest in legal and policy remedies for workplace issues in the health care sector. As such, I am in the process of applying to law school.



A Threat to Selfhood: Moral Distress and the Psychiatric Training Culture

Esther Nathanson

While many medical specialties offer to heal, or even cure, psychiatry—uniquely—places the doctor–patient relationship at the center of the therapeutic effort. Psychiatrists must possess a complex and challenging combination of broad medical knowledge, finely honed interpersonal and analytic skills and confidence in their abilities, despite limited understanding of the workings of the brain. Inpatient psychiatry in particular demands a degree of strength to withstand emotional, and sometimes physical, assault from patients who may be suicidal, desperate, paranoid, aggressive or delusional. Beyond these abilities, a good psychiatrist must have robust but ‘therapeutically porous’ emotional boundaries that allow genuine empathy for the patient but, at the same time, limit internalization of the patient’s anguish as the practitioner’s own: the exquisite balance of ‘self-versus-other’ in the therapeutic encounter.

Unfortunately, during my psychiatry residency in the UK, development of these intangible but essential boundaries was entirely absent from the curriculum. Early in training I struggled with my tendency to become an emotional chameleon with feelings and energies buffeted around by the prevailing emotions of each patient that walked through the door. I felt that patients expected me to offer tidy explanations for their suffering and provide answers to profound questions of meaning; to make the world a safe and understandable place. Given the complexity of mental illness and its interplay with social circumstances this was naïve and, I now realize, often unnecessary, but the weight of responsibility was unbearable. I was also completely unprepared for the intensity of human suffering I saw, and wholly unready to provide the level of interpersonal engagement required for genuine healing. My own emotional integrity felt threatened by the depth of patients’ needs, and my response—both physical and emotional—was intense and frightening.

Much of my distress resulted from the profound and inevitable tension between the empathy necessary to comprehend patients’ experiences, which were often extreme and bewildering, and the need for resilience and self-protection at a time when my grasp of psychological theories and treatment practices was still rudimentary. I felt guilty that patients bore the brunt of my inexperience, and duplicitous purporting to help while burdening them with intolerable drug side-effects and stigmatizing, albeit effective, treatments such as electroconvulsive therapy (ECT). Time constraints and guidance from senior faculty encouraged expediency over treatment efficacy or durability; psychopharmacology was prioritized over the psychotherapeutic techniques and psychosocial interventions I found more effective for many patients. During the phase of our training that took place in a rambling, now defunct, asylum in the U.K, visits to the locked ward, which was reserved for patients considered a danger to others, were usually prompted by nurses’ requests for chemical restraint, the ‘pharmaceutical strait-jacket’. I was deeply uncomfortable with the role of ‘restrainer’ but had insufficient experience or seniority to propose other methods. It was only when, years later, I investigated re-training in the U.S that the senior psychiatry resident at a well-known program told me gently, ‘Oh, we assume that students will have a breakdown in their first year, so we have systems in place to help’. I’ll never forget those words; they are, to this day, the only validation of the emotional toll of my early training years.

Adding to my discomfort were various ethically dubious administrative practices, the most troubling being the clinic’s unwillingness to disclose to patients that we were trainees, with little clinical experience. Senior faculty were dismissive when I asked whether my first psychotherapy patient had been told I was a trainee, indeed that I had never conducted psychotherapy before. My question was greeted with amusement and an assurance that, although she had not been told, I (not the patient, interestingly) would do fine.

Due to the large number of no-shows in psychiatric outpatient clinics it was also standard practice to triple-book appointment times on the

assumption that one or more patients would fail to attend. Not uncommonly, more than one patient would arrive for the same appointment, leaving others to suffer agonizing waits that were often intensified by the deep discomfort many felt about seeing a psychiatrist. I frequently saw patients pacing or wringing their hands in the waiting room. This issue was exacerbated by an outpatient scheduling system that failed to take into consideration the days that we were on call. Invariably I would be called away to an emergency during clinic time, leaving a waiting room full of patients who would eventually be told I was unavailable and they should come back another day. I felt complicit in a system that made me deeply uncomfortable and in which my beliefs and sympathies were misrepresented.

With some memorable exceptions there was also a system-wide lack of support from senior physicians. Despite working in an environment where patients' emotional turmoil was devoid of stigma, the reigning culture viewed emotional distress among physicians as a weakness. Some senior faculty considered me "overly sensitive" or simply unsuited to the profession. In one case I was explicitly told that if I couldn't stand the heat I should just get out. If fellow trainees suffered similarly, it was in silence.

Whereas it is now acceptable for physicians with moral concerns about a particular intervention to pass this aspect of care to a willing colleague, no such mechanism existed then and there was no contingency plan for back-up care should a healthcare provider be a "conscientious objector." I found myself holding patients down for sedative injections and, under senior instruction, prescribing medications that simply covered up the problem until it resurfaced. In pursuit of the first professional milestone in psychiatric specialization I fulfilled numerous requirements that I found morally troublesome. These included participation in the twice-weekly ECT rota; prescribing medications that I believed did more harm than good; and conducting six months of weekly psychotherapy with a troubled young woman who had entrusted her wellbeing to me despite my inexperience. I wish I had known the term "moral distress" back then;

being able to name my feelings would have made them feel more legitimate.

I experienced moral distress as depression, panic attacks and crippling depersonalization. Depersonalization, and the state of de-realization that commonly accompanies it, are bizarre and deeply unpleasant experiences in which you feel as though you're unreal and in some way detached from yourself and the world around you. Although healthy people in states of extreme emotion may experience something similar, the pathological state is associated with an intensity and duration of feeling, and degree of anxiety, that are far more debilitating. In my case, symptoms would last many days, sometimes weeks, at a time; weekends were often better but when Sunday night came around they would start again. My symptoms escalated rapidly when a patient entered my office and were so overpowering that it was almost impossible to carry on a normal conversation. I would start sweating and feel an urgency to leave the room; parts of my body felt as though they didn't belong to me and my words seemed to come out of a mouth that wasn't mine, and hang in the air between me and the patient as though spoken by someone else. I felt as though my feet didn't touch the ground when I walked. There was no medicine that provided relief and the only way to alleviate symptoms was to remove myself from stress-inducing situations. It was hard to tell whether my extreme anxiety was a feature of the disorder or whether my fear that I was behaving strangely caused the anxiety. Indeed, part of the problem seemed to be the relentless drive to understand what was happening and why, which drove me to many hours of (usually unproductive) self-examination.

Because full-blown depersonalization disorder is uncommon, my symptoms remained undiagnosed for eight years, despite visits to a wide variety of doctors—neurologists, psychiatrists and balance specialists—and several brain scans. I was told more than once that I was fine and just having a rough time or, in one case, that I was suffering from nothing more than coming from a neurotic, middle-class Jewish family (really, this was the 'diagnosis'). In the end, long after residency, I diagnosed the condition myself and the diagnosis was later confirmed

during a clinical trial I volunteered for, my sole purpose being to find out whether my self-diagnosis was correct. The relief at finally having a name for my experiences was indescribable. Now, after several years of psychotherapy with a psychiatrist whose compassion, wisdom (and yes, boundaries) somewhat restored my faith in the profession, I am almost symptom-free.

If there was meaning in my experience it was in forcing me to confront what I am and am not willing to compromise, as a human being and a healthcare provider. When I looked at colleagues with many years of psychiatric practice under their belts I saw people who were demoralized and emotionally disengaged; compassion fatigue and burnout were widespread. These senior colleagues could listen, prescribe, provide advice and continuity of care but very few had maintained (or perhaps even achieved?) the sophisticated balance of compassion and self-protection that allows someone to inhabit another's world with genuine human connection. I was alarmed by the path I was on and confident that I needed to step away from this environment—perhaps temporarily, perhaps permanently—to re-evaluate my personal and professional goals and priorities.

Deciding to take a break from clinical training was a difficult step. I didn't know of anyone who had done this and I hadn't realized the extent to which my identity was based on being a physician. Letting go of this made me feel strangely vulnerable. There was no career guidance for physicians considering a change of direction. Although it was a time of great uncertainty, as I regained perspective I realized that the gulf between the person I was (and wanted to be), and the person I would have to become in order to survive the profession, was simply too wide. I knew that further training might help but I couldn't stay in an environment that was so emotionally destructive. I was unwilling to compromise my humanity and compassion for expediency, professional advancement or fear of leaving the profession.

I left the residency program and applied for a position as a medical writer with a start-up medical communications company, glad to have found a job that made use of my medical knowledge but not my

emotions. I've now worked for this company for more than twelve years and recently enrolled in a bioethics Masters program here in the United States, where I've lived for 11 years. My goal is to move towards a career that makes use of the knowledge and skills I learned as a clinician, the writing skills I've developed in my current job and my interest in clinical ethics.

I left psychiatric training deeply saddened that I hadn't found a way to survive it but confident it was the right decision. Given the demands of the job and its toll on individual practitioners, effective psychiatric training needs to anticipate and screen for emotional difficulties in a non-judgmental atmosphere of acceptance and support, and implement programs to address them. Instead of viewing personal struggles as weaknesses, it might be more productive to see them as indicators of empathy and moral strength that, if harnessed effectively, can strengthen the individual and the profession.



Black Horseman Lane: A Reflection

Janet Pniewski

I felt a sinking feeling in the pit of my stomach upon getting the news this particular patient, let's call him Stan, had burned through yet another nurse case manager and it would now be my responsibility to take charge of his care. As the medical director read aloud his patient profile, "Sixty-eight year old frail appearing Caucasian male with a terminal diagnosis of . . ." I was already formulating excuses in my head as to why I would not be able to accept this charge. However, when she finished, I dutifully replied, "Ok, I'll give it my best shot." At the time, I was well aware that this assignment would test my resolve and commitment to providing the same high quality compassionate

**Names changed to protect privacy.*

care to every patient, but what I did not realize was how much I would grow personally and professionally in the process.

Stan was well known in the organization for being “non-compliant” and “difficult.” Through his past actions he earned the label of racist and misogynist, having zero tolerance for people whom he perceived as different from him in any way. He was profoundly disrespectful toward women and was known to abuse his animals. Having been raised in a liberal household in New Jersey, surrounded by civil rights activists, animal activists and feminists, I was genetically programmed to abhor social injustice and raised to serve as an advocate for the disenfranchised and vulnerable. Since childhood, I’ve experienced visceral reactions to acts of injustice or cruelty of any kind. The very idea of someone like Stan was appalling.

I found myself assigned to Stan’s case by default. He fired his first nurse because she was African American and painted her as dishonest and incompetent. He fired his second nurse because he was male and therefore must be gay. He fired his social worker because she was overweight, which certainly meant she was lazy. He fired the chaplain because he was not Catholic and thus unworthy of having any meaningful spiritual discourse. He would not accept the recommendations of our medical director because she was a woman. His family had given up on him a long time ago. His wife left him shortly after his youngest child had gone off to college, and all four of his children were estranged. Stan’s disease was progressing, despite therapy, and he was becoming too weak to care for himself at home without hospice support. His oncologist pleaded with us to give it one more try, even though we were running out of staff. These people that Stan had dismissed so unpleasantly were my colleagues and friends. The first nurse Stan dismissed served as my ever patient and knowledgeable preceptor when I was new to hospice and fumbling my way through unfamiliar protocols. The second nurse Stan rejected was a dedicated colleague and devoted friend, supporting me through several life challenges. I had witnessed our chaplain, judged as unworthy by Stan, tirelessly provide comfort to patients, family members and staff members in the

darkest of hours. I knew them all as well-meaning, competent and compassionate team members and Stan’s disrespect for them offended me.

Apparently, Stan was offended as well. His oncologist revealed to us that Stan was angered by his referral to hospice. He felt abandoned. I was Stan’s last hope; however, he didn’t see it that way. Neither Stan nor I was enthusiastic about our impending partnership.

Stan was an engineer by trade, and apparently very successful in business. He lived on a sprawling plantation located at the end of his private road, which he named Black Horseman Lane. As I turned down the drive, aware of his reputation as a bigot, I contemplated how Stan might have arrived at this name. With the assistance of my smartphone, I was able to ascertain that there was, indeed, a Black Horseman of the Apocalypse, which was associated with famine. Delving further, into Wikipedia, my interpretation was that the Black Horseman’s famine decimated the grain crop, sparing the olive groves and grapevines, driving up the price of grain but leaving oil and wine supplies unaffected, though out of reach of the ordinary worker. This selective scarcity resulted from injustice and the deliberate production of luxury crops for the wealthy over grain. This Black Horseman may not have had the racial connotation that I imagined, but alas, Stan was an extreme right-wing capitalist who believed in social hierarchy on the basis of natural law, leaving vulnerable populations to fend for themselves in times of famine! I had whipped myself up into a frenzy of utter disgust for this man, based on his reputation and my own overactive imagination fueled by my unfortunate access to Wikipedia. Now I was certain that I would not be able to care for him.

I arrived in front of the house, safe, for the moment, within the confines of my vehicle. With a deep sense of dread, I slowly opened the car door and made my way to the door. I was immediately offended by the black lawn jockey and saddened by the pitiful, emaciated dog that greeted me in the driveway. I knocked repeatedly on the door and a momentary wave of relief washed over me with the thought that he may not be home. The sick feeling of dread returned as I remembered the instructions left

by the social worker to use the lockbox. Stan spent most of his day in bed asleep and made it quite clear that answering the door “to let the vultures in” was not a priority. I begrudgingly used the key to let myself in through the carport door. In stark contrast to the bright sunshine of a beautiful crisp autumn day, the house was dark and musty with every curtain drawn closed. The décor looked like a hunting lodge exploded inside of a monastery. Animal heads hung next to crucifixes on every wall. I looked for family photos, but none could be found. I followed the sound of a blaring television, a Catholic mass broadcast, which later, Stan advised was left on 24 hours a day. Hidden away in a back room like a dirty secret, I found Stan.

The smell of urine and cigarette smoke was overpowering. I lowered the volume on the television. Stan was lying in bed sleeping, extremely ashen and frail or was he dead? I gently placed my hand on his shoulder and whispered, “Stan, I’m sorry to wake you.” He opened his eyes briefly. “Who are you?” he said, “one of those god damned vultures . . . you’re too skinny . . . you look like a god damned clothes hanger.” I extended my hand and said, “My name is Janet. I’m a hospice nurse.” He ignored my outstretched hand, threw off his covers and proceeded, stark naked to the bathroom. “Stan, would you like your bathrobe? I wouldn’t want you to catch a chill,” I said. Stan replied with “I’m sure you’ve seen plenty of dicks . . . probably up close and personal if you know what I mean girly.” With every fiber of my being, I wanted to run out of that house screaming. It took every ounce of self-control I could muster to remain in that room with him and retain my composure. That was my first meeting with Stan.

My first few visits to Stan’s house were extremely difficult for me. I had to really psyche myself up, channeling my inner Mother Theresa. Ideologically, we were worlds apart and Stan was easy to dislike. After a few visits, I became accustomed to his insults and somehow no longer took them personally. This was clearly not about me. Stan was in a lot of pain, both physically and emotionally. My nursing education and my upbringing emphasized that each person deserves to be respected and cared for as an individual, despite who they may be, and that

each person is inherently valuable. As a nurse, as well as a human being, I knew I could not turn my back on Stan. He needed a hand.

First, with much discussion amongst the interdisciplinary team, but with Stan at the helm, we got his pain under control. I took the initiative, with Stan’s permission, to call his children and offer an update. I became the liaison between Stan and his children, and although Stan had no relationship with them, he appeared eager to hear how they were doing. His children were appreciative of our presence, finding it comforting and relieving their guilt. It became clear that Stan, too, was comforted by our presence and did not want to die alone. However wonky, we had made a connection.

As Stan became sicker, and closer to death, he softened even more. I found myself visiting daily, not to fulfill any skilled nursing need, just to offer my presence. I spent many hours at his bedside listening to stories from his childhood, which was less than ideal. He reminisced about “the good times” when he and his wife were “courting” and his regrets over his failed marriage, which he attributed to his “attachment to the bottle.” He recounted the birth of each of his children with a glimmer in his eye that I had not seen before. He told me the story of the emaciated dog, “Walter” who had greeted me in the driveway. Walter had also been diagnosed with cancer and Stan did not have the heart to put him down. “One of us having a death sentence was enough,” he said. He asked me if I would see to it that Walter got the care he needed. I agreed. Oddly enough, we talked about the black lawn jockey. Stan told me the story of Jocko Graves, “The Faithful Groomsman” and made me promise to tie a green ribbon on Jocko the day he died. We talked about what his death might look like and I promised I would not let him be in pain. He made me promise that I would let him be in “some pain” because after all “to be a good Catholic you have to be in pain.”

Stan also revealed that he used to be quite an outdoorsman. I told him that I gathered as much, with all those heads hanging on the wall. He revealed to me that while he hunted with his grandfather when he was younger, later in life, he enjoyed shooting animals only with a camera. He had me dig out his photos, which he regretted never displaying

or sharing. “Who would I show them to . . . Walter already saw them . . . he was with me,” he said. I admired a beautiful photo of a big strapping buck rubbing his antlers on a huge maple tree with fiery red leaves. “That was one of my best days ever in the woods,” he said. “I want you to have it, please.” I thanked him. He talked about how he loved the cold winter air on his face when poised in his deer stand and yearned to be out in the sunshine, but was afraid to leave the house over the past several months in his weakened state. On one of the last days that he was able to talk, he thanked me for hanging in there with him, saying “you’re not just a nurse . . . you’re an angel” and chuckling, ended his sentence with “god damned clothes hanger.”

The day Stan died was a beautiful, sunny and cold December day. I stayed at his bedside and held his hand all morning. He appeared peaceful as Walter lay at his side with his head rested on Stan’s lap. Around noon he started Cheyne–Stokes breathing and I knew he was getting close. After about an hour, heaviness started to build in the room. Stan needed some additional help moving on. Intuitively, I pulled back the heavy curtains and threw the window wide open. Bright sunshine came streaming in along with a brisk winter breeze. About a minute later, Stan took his last breath and he was gone. I had a good cry before telephoning each of his children and the oncologist. Loading Walter in my car, I drove down Black Horseman Lane for the last time.

My experience with Stan illuminated the importance of personal knowing and mindful reflection in my nursing practice. Personal knowing requires that I be in touch with my authentic self, so that I may live my life with deliberate intent; my actions become harmonious with my deepest intentions. My deepest intentions are directed toward the relief of suffering and fostering connectedness. I may not have been able to offer a cure for Stan’s cancer, however, I could offer the opportunity for him to make a meaningful connection and possibly relieve some of his suffering.

Mindful reflection requires an attunement to the present moment, release of judgment and an orientation that is curious, open and accepting.

Facilitating authentic and reflective experiences in my interactions with Stan interrupted habitual impulses and reactions and created space for a healing relationship. Through this process, our interactions became less automatic and more creative . . . less reactive and more responsive . . . less impulsive and more relevant. Through mindful reflection and personal knowing, I was able to make sense of the awful feeling in the pit of my stomach and make a conscious choice about the kind of nurse that I wanted to be for Stan. Through this process my actions became more genuine, authentic and in harmony with what I always would choose to be: compassionate and caring.

My experience on Black Horseman Lane and with mindful reflection has had a profound impact both personally and professionally. Reflecting on my experience with Stan has made me more conscious of my own motives, fears, needs, feelings, perceptions, attitudes, and habits. As I weave mindfulness in to my everyday practice, I become less reactive and more able to respond appropriately to people and situations that may have been more challenging in the past. As I grow more attuned to myself and others, I have become a more effective communicator, enjoy healthier relationships and have more of a sense of fulfillment with work and with life.



These Things I Believe

A. M. Shuham

I am a health care professional who has worked in the field for two decades. I have been part of small miracles and heartbreaking events, which kept me up at night. Although I do not

**This case has been de-identified by removing or changing all names, ages, geographical identifiers and any other information that could compromise patient or family confidentiality.*

provide direct patient care, my advanced education and expertise allows me to advise members of the health care team when difficult questions arise about the goals of treatment, questions about competency and interpreting patient preferences. I believe my interest in the field was shaped by my family's experience dealing with the challenges that come with terminal illness and advancing age. I am humbled to have been part of their journey as they faced death with dignity and grace.

Living in a small community presents significant challenges that may never occur in a large urban setting. The team you work with knows your family or the names of your children because in their spare time they are the piano teacher or soccer coach for your children, friends that knew you growing up. This close knit atmosphere can be a blessing when things go well and unbearable when mistakes are made or professionals disagree, because you still interact with one another outside the context of your professional role and this is when moral distress begins.

I began working with A. J. ten years ago to facilitate the completion of a health care directive. At the time A. J. was beginning to show the signs of a neuro-muscular disease experienced by other members of the family. In early 2000 most directives were fairly straightforward with the option to choose artificial nutrition and hydration or not. A. J. very specifically checked "none." Years went by living independently for A. J. but as most illnesses progress so did A. J.'s, and admission to a health care institution became necessary. In many situations medically assisted nutrition and hydration would be indicated, but in this case the wishes of the patient were known in the form of a health care directive. The decision makers inability to honor the directive was the purpose for my involvement almost a decade after my initial work with A. J.

No matter where you stand in the debate regarding medically assisted nutrition and hydration being burdensome or ordinary care, most people believe in the importance of a health care directive given the histories of Nancy Cruzan, Karen Quinlan and Terri Schiavo. My objective was to compile the legal information that would elucidate the patient

preferences and help staff and the decision maker understand it was time to honor the directive given the advanced stage of disease. Numerous attempts were made with the surrogate and health care professionals to help them understand state statutes on health care directives supporting a patient's right to choose. It became clear that some of the team seemed disinterested in my concerns or my responsibility as a professional, and I began to believe the difficulty was a failure on my part to communicate clearly.

During that first year conversations and meetings were scheduled with the patients decision makers and they felt unable to make a decision and requested the entire family provide input. Although they understood A. J.'s wishes, they felt everyone should be in agreement. In my experience when leaving decisions of this magnitude to a large extended family, communications deteriorate and little can be accomplished. Some members in the family held fundamental religious beliefs and thought a miracle could change the prognosis. While I believe as health care professionals we must respect individual religious beliefs and values, we are also morally obligated to advocate on behalf of our patients a fundamental principle I hold dear.

The health care team was no more eager to address the issue than the family. I had produced specific state statutes regarding the health care directive of a previously competent person and even in light of this information, some individuals continued to believe the surrogates decision took precedence over the directive. This growing tension left me feeling angry and ineffective, questioning my role in the organization, while watching A. J. linger in a state not chosen. I believed I had failed in my obligations as a professional.

In any organization there are multiple layers of legal checks and balances to ensure compliance, quality, organizational integrity and the law. I had produced the state specific statutes regarding the obligation of a health care surrogate to honor the written wishes of a previously competent individual and even so this case would migrate from one arm of the organization to another with the hope

that I would simply go away. I began to feel like a caricature, that stick figure of a person pushing a large boulder up a steep incline. I found myself avoiding direct eye contact with individuals directly involved in the case and angry because I let A. J. down during the most crucial stage of life and just when I began to feel that boulder rolling downhill, the weight of this case shifted.

The Court requires an annual report with information that the guardian is in compliance with the duties established in the original adjudication. The court visitor contacted me about my perspective, and at this point things began to change with the legal system's acknowledgment that the health care directive must be honored.

The health care team anticipated A. J. would deteriorate but to everyone's surprise A. J. began taking food and water by mouth and with attentive feeding techniques weight has been maintained. The progression of the disease continues while at the same time quality of life for A. J. has improved. I am confident the remaining time left will be spent the way A. J. wanted and placed in writing years ago.

When you work in a small community your patients may be part of an extended family you have experience with and your colleague's may share the same dentist or shop at the same market. This is when pleasantries are exchanged when what you really want to say is inappropriate. I cannot say with certainty that working in a larger area would have decreased the tension or frustration I experienced, but I do know that based on the outcome, I sleep better at night.



"Please Help Me"

Rebecca L. Volpe

Two-year-old Jay was born prematurely at 26 weeks gestation, addicted to opiates. After several months in the Neonatal ICU,

he was sent home, ventilator-dependent but with a high likelihood of survival and a low chance of severe, lasting disability. When Jay was 1½, he had a cardiopulmonary arrest at home. The parents of children who are on ventilators at home receive extensive education and training about how to respond to something like an arrest. They are taught that a quick response is often critical to their child's long-term prognosis. And yet, Jay's parents took such a long time to respond to his code that Jay now has severe hypoxic ischemic encephalopathy: his brain was deprived of oxygen for so long that he has no higher cortical function, and will never think, speak, walk, or play.

Currently, Jay is ventilator-dependent and has a very poor prognosis. Jay goes back and forth between a nursing home and the hospital. During one of his many hospitalizations, the ICU team decided to call an ethics consultation, because they felt that continued aggressive intervention was no longer in Jay's best interests. I was the person on the other end of the line when the medical team called. After having a brief conversation with the attending physician, I left my office and walked to the Pediatric ICU to visit Jay. I arrived at the bedside—really just a large crib—and saw a baby with dark hair lying flat on his back. His tongue was swollen and protruding from his mouth, his eyes were puffy and closed, and his limbs were limp. On his belly was a piece of paper with the words, "BECKY PLEASE HELP ME" typed in huge, bold font. I looked up, into the eyes of the attending physician and said, "Did you type that?" The physician nodded yes. Much could be said about this physician's behavior. But the bottom line—from a clinical perspective, at least—is that this ICU team was desperate, and that they had significant expectations that I would be able to help them.

I began the work of the consultation. I reviewed the medical record, spoke with members of the treating team, and set up a time to talk to the family. During the family meeting, I learned that Jay's parents wanted to continue to treat aggressively, and that they believed it was not their place to decide when it was their son's time to die. That was

God's decision. They could not fathom removing interventions that were maintaining their son's life. They acknowledged that his quality of life was not high, but, still, it was *life*.

The preferences of the treating team were in stark contrast to the parents' preferences. The neurologists believed Jay did not have the capacity to experience physical pain, but the ICU team believed that continuing to treat Jay was cruel. Although the ICU team acknowledged that Jay was *probably* not suffering, they noted that we could not know for sure, and that sometimes Jay grimaced and withdrew—signs that are often interpreted as suffering. The ICU team also argued that given all the sick children in the world, and the scarcity of healthcare resources, it didn't make sense to invest hundreds of thousands of dollars into prolonging Jay's life. Additionally, they discovered that Jay had osteopenia (weak, brittle bones)—which was causing multiple bone fractures. The ICU team anguished over the thought of Jay's small, soft bones continuing to break despite their best efforts.

The bioethicist in me knows that, as long as the patient isn't suffering and the parents aren't demanding futile interventions (they weren't), our role as providers was not to judge the parents' value system. I told the ICU team over and over that different people place different value on Jay's type of life, and that it wasn't for us to tell them that their value structure was wrong. I talked with other members of the clinical ethics consultation service. Then I brought the case to the entire institutional ethics committee. I was hoping they would tell me I was wrong—that I could legitimately and within the bounds of my professional role tell these parents that the decision wasn't up to them anymore. But they didn't. I can't remember ever being more disappointed to be right.

On a personal level I agreed with the ICU team: it wasn't right to continue to treat Jay aggressively. But from a professional perspective, there didn't seem to be a lot of wiggle room. I hit the books, checked state law, and worked with in-house resources, but everything I learned confirmed what I already knew intellectually: this was the parents' decision.

I told the ICU team, "This isn't what I would want for my child, but . . ." It was incredibly difficult to try to persuade the medical team—who were becoming angry that I was not telling them what they wanted to hear—of something that I personally didn't agree with. I was advocating for a route that I found personally repugnant.

In my role as the clinical ethicist, I am in many ways powerless. I'm not the one who writes the medical orders. I'm not the one who is legally responsible for the patient's care. And I'm not the one whose value system should guide moral decision-making at the end of life. When educating about the role of the ethics consultation service, I often say that providers don't call an ethics consultation because they want to know my personal opinion. They call because they want to know what the ethics literature has to say; they want to know about institutional policy, or state law. My challenge every day is to *remove* my own value structure from my work. I stand by this perspective. But living it is hard.

Jay has had a striking impact on my life over the last year. I use his case as a stepping off point for teaching residents about medical futility; I assign it as an essay for 4th year medical students; and I recently did a bioethics webinar exploring the differences between futility and worth that relied in large part on Jay. I sometimes wonder why I've incorporated his story into so much of what I do professionally. Wouldn't it have been easier to simply forget?

But by exploring and re-exploring Jay's case with a variety of people, I get to learn from others how they would handle it; I get to hear their insights, their inevitable frustration, and their sadness. This process is therapeutic for me: I feel as though we are learning from Jay and making his life about something more.

When Jay first came into my life, it was agonizing. That night at 2 a. m. lying in bed awake, I deeply and thoroughly wanted to sneak back into the hospital and unplug his ventilator. Of course I didn't. The next morning I felt a deep sadness in my chest; the knowledge that a small child was

suffering, and that I *could* do something about it, if only I *would*. Even now, a year later, it makes me sad to think about Jay. I feel a physical weight on my chest, and sometimes it's hard to breath. I'm not sure how to deal with my continuing moral distress. I think, though, that it's actually good that these cases upset me. This is the job; these are the choices. My angst is perhaps a hallmark of caring. I hope I never stop caring.