MORAL DISTRESS IN HEALTHCARE: THE VALUE OF DYING WITH DIGNITY

CORRY ROACH R.N., CPNLP, was a student of the late Elisabeth Kübler-Ross and the late Gregg Furth, and employs their work in her private therapy practice today. Her first book was *By Grace of Mourning*.

Recently I watched my only sister lose her battle with Acute Lymphoblastic Leukemia, after complications from severe post-graft-versus-host syndrome infection. It was five months from diagnosis to her death at 46 years of age. As she was a brittle diabetic since birth, I became more of a mother to her than a sister over her lifetime, as nearly a decade separated us in age. It was almost like losing another child for me.

In 1983, as a bereaved young mother to my infant daughter, I sat in on a lecture by the late Dr. Viktor Frankl, which dealt with ethics around the care of ill and premature babies, and the value of dying with dignity in those situations. I took issue with the fact that, despite our insight and technological progress in healthcare, we were losing sight of holistic care of the human person, physically and emotionally as well as intellectually and spiritually. It appeared to me that the further we progressed technologically, the more we regressed in our compassionate care for dying people and their families.

There is no doubt that I spoke at the time from the place of a broken-hearted mother. Perhaps I was too young, naïve, or afraid back then to speak my truth about how we deal with dying in our western culture. Now, a few years past a half-century in age and well into menopause, that part of me has changed considerably!

Despite this fact, however, I don’t feel that my concerns had any less merit. This same concern arose again with the death of my sister.

I am aghast that, 25 years after my baby died, there appears to be little change towards the question regarding the value, meaning, and humanity in being allowed to die with dignity, if I respond with painful honesty to what happened with my sister last month.

I wanted to secretly take photographs of her dying body, bleeding, blistered and burnt beyond recognition, since my fear was that no one of consequence would believe me.

I recall feeling the same way when I asked Dr. Elisabeth Kübler-Ross to look at the only two photographs I have of my beloved baby, who physically looked very similar as a result of a severe megableeding disorder. Elisabeth’s initial response was to dismiss them as well.

That was before she caught a glimpse of the images, and then she gently took them from my hand. Asking if she could pass them around to everyone in the room, she
said, “Especially health care professionals need to see this, to ensure that other little babies will not suffer as your baby did. This must not be allowed to happen again.”

Well, it has happened again, and in my family. Ever one to find deeper meaning, I see this as an opportunity to become an advocate for patients who need to die when their suffering becomes obscene, and they somehow are not able to make their request known or respected.

There can be reasons for this due to extenuating circumstances, as was so with my sister. I believe the fact of her being diabetic complicated sending her to palliative care when she was on insulin via PIC line. Although she got analgesia through this line as well, the continuous infusion prolonged her inevitable dying process. I understand how these issues make things more challenging to give optimum care.

On one of my last visits with her, she looked like a taller version of herself as a newborn, except that she was horribly blistered, burned and in terrible pain from the caustic treatments. They were making her desperately ill, with half-hour cycles of retching, nausea, vomiting, abdominal cramping, and bloody diarrhea along with fever and chills. Flaps of skin from open blisters hung from her torso, neck, arms, and hands. Tears, staining white against her ruddy burned cheeks, coursed into the corners of her mouth. In her pain, they would spurt from her eyes, but I could not wipe them, as her skin would invariably come with it to create more bleeding. The mucous membranes of her mouth, eyelids, and intestinal tract were so scorched they too came away, leaving her raw and bleeding, inside and out.

As I crouched beside her after another bout of dealing with the brutal side effects, I commented to her about her quiet, pensive expression. After a long moment of silence, she said softly, “I don’t know what else I can do to help myself...”

It was the perfect opening into our discussion about her desire to die. The dialogue around the unspeakable began to mould and take shape from that one sentence, empowering her to listen to her own heart’s desire.

I am enraged and sickened as a person, and stunned and mortified as a nurse, that this kind of thing can continue to occur. We are ever expanding our knowledge with regard to science and technology, but we spend less time being human in giving compassionate care to the dying and their families.

Time spent on computers is time spent away from the pain-riddled, desperate, and often fearful patients who cannot articulate their needs swiftly enough for the busy medical and nursing staff. They, in turn, don’t have time to internalize what needs to be done to meet the patient’s personal/psychological/spiritual needs instead of the technological demands of the machinery attached to the physical patient.

Although I spent nine hours with my sister while she was ravaged by the effects of the treatments, I could not embrace her to bring her comfort; it was too painful for her to be touched. Blinking her eyes caused her severe pain. We could not clean anything to attempt to rid her of the cancer smell. Maintaining an airway had to be done without suction, again due to bleeding. Her head was wrapped with J cloths to stop the serous fluid oozing from her scalp, leaving a copious stain on her pillow every few hours. Sometimes she physically shook as her teeth chattered with pain.

My daughter, who is a post graduate nursing student, and I resorted gratefully to our practise of alternative therapies of Therapeutic Touch and Reflexology, and our
gentle intervention calmed my sister so she could deal with her pain more effectively… so we could have that discussion.

I somehow already knew it to be the reason behind our visit. Call it intuition, my spirit knew. My love knew.

My sister wanted to die. In my work, I have had many of these quiet, calm discussions, and I try to listen with every cell of my body and spirit. I want to be sure that they are sure.

She was sure.

In expressing this fact to the nursing staff a few days later, they were unaware of this choice, despite her obscene physical state and the fact that treatment had now been stopped. Although our continued discussion verified the accuracy of my sister’s condition, I was surprised that there had been no pastoral care intervention with regard to this. I was grateful for our attendance.

A few days passed. She was left to thrash about in semi-consciousness on bed rest now, until someone realized what the thrashing really meant, since she could no longer communicate verbally. She was prescribed Fentanyl breakthroughs every six minutes for pain, but had no way to push the button as her hands were contracted and she was no longer lucid. Delirious, she was now bleeding from her nose, mouth and eyes. We could not begin to clean anything, as she almost spontaneously bled.

Watching this, I was beyond speech. There are no words…

If she had been a dog, some compassionate person would have euthanized her by then to put the dear woman out of her misery.

I was so immersed in my compassion and attention to my sister’s constant needs, I had no room at all for mine. I held off, strong and caring, without my own pain getting in the way… until the next day at home, when I could wail, cry, and rant on my own. And let go, again and again. I was aware I needed to clear my emotions in preparation for the next visit, as they had no place when I was with her. I didn’t separate my roles as mother, sister, or nurse in this situation; I just knew I was of greater value utilizing my professional skills along with my love. This, after all, was long ago not about me anymore.

As an RN who has worked in the field of death and dying for the last 25 years, I observe how we deal with death in our western culture. We regard it as a bitter enemy to be feared, fought, and avoided at all cost; yet my personal and professional experiences tell me that death is not the enemy at all.

It is not the greatest tragedy that my baby and my sister died; I can accept their death. The issue I struggle with is how they died—heroic obscene struggles of suffering that made the alternative of death a gift of peace. How sad when we somehow regard it as a failure when all interventions are ineffective and death prevails.

I feared my sister’s body would be in the early stages of rot and decay, just as my baby’s was by the time she finally died. Why? How is it possible that this happens in 2008?

As caregivers, we sometimes lose focus on the person who has the disease, and work in isolation on curing, killing, or healing a disease with which the patient is afflicted. We forget the package deal—the two come together! The more we advance in computer technology, the fewer meaningful interventions of contact or personal care our
patients seem to experience. We become so focused on analysis of implications and indicators of pathology that we forget about the person as a whole.

In those nine hours of caring for my sister that one day, I never sat down once in attending her constant needs. Nurses came into the room only to deal with the intravenous solutions and medications. No one touched her, of course; only one person spoke to her directly.

As a nurse, I can understand this; we need to assure medications and their administration are done efficiently and on time. My sister had eight lines running at the time. Again, it’s an observation, along with some deep concerns about what it means to be a nurse these days.

I’ve been around a long time, and remember giving back rubs to patients… That was another era indeed!

However, I am left helpless and bereft, as a human being and as a nurse. This is accentuated by the fact that I remember there is a better way; it has been lost along with that personal bedside care that has been swallowed up in technology. There is nothing that can replace the calm, soothing presence of a caregiver at the bedside of a dying patient.

In our CARNA nursing library, there are four books on the topic of death, dying, and bereavement. Four. I am stunned at why we are so inept in caring for the dying in our culture. We need to take lessons from those ancestors and cultures that live so close to the earth, those who recognize grace, humility, and acceptance when the right to exist has passed and the right to die has begun. Death is not the enemy—ignorance is!

In our approach to the spiritual question around care, we are remiss in our presence of listening to the patients’ concerns or conclusions, particularly if they do not match our own. It is my firm belief that we not only can but must learn to stand steady with the patient’s journey of belief, and not get caught up in the differences. It is not the destination, but the manner in which we as caregivers support the journey that is of credible import here.

I believe we are all on a spiritual quest of meaning in this life. I believe we often confuse spirituality, whose purpose I feel it is to embrace the oneness of our humanity, indeed all things living.

Religions, in how they are practised for the most part in the world, are much more divisive in nature, in my experience of them. It is my humble observation that we can only assist this confusion into clarity if we, one person at a time, come to know the Truth of these matters in our own personhood first, both in heart and in mind.

In integration of beliefs and personhood, I then have that also to offer my fellow man, regardless of their race, creed, color, education, gender, or beliefs. This takes much less energy in maintenance than the divisiveness that my ego brings to the interaction, in my experience. I can accept and respect others with greater ease, because I know myself and how my spiritual nature sustains me, so I can sustain others…

In non-judgmental attendance, we are given the opportunity to expand our own experiences and references of realm. It is my personal faith that we are all remarkably the same, despite our differences in belief systems. Peace comes to all who celebrate this Truth.
It is here that the study of holism and spirituality becomes of dire importance in how we deliver healthcare to the dying in our culture. I am of the personal view that it does not matter what path of spiritual or religious unfolding, introspection, or evolution occurs, but that we must, as healthcare providers, be comfortable in acknowledging its import in the discussion of end of life care. Cultural and spiritual belief systems play a significant role in these issues, and I mean no disrespect when I share my thoughts.

Unfortunately, I believe that, despite our technologically advanced skills, we have much to catch up on where our skills in embracing the needs of those who care for the dying (as well as their patients) are concerned.

It is my belief that all roads lead Home. If we fear death as caregivers or see it as failure, those judgments color our care and compassion for the patient in their dying process as well as the loved ones who attend them. We cannot serve them as fully or give of ourselves as freely if we have unfinished business around these issues.

We need teaching and guidance in this regard as caregivers, on a personal level, so that we might integrate them on a professional one. This will allow us to be present and integrative in our care of the dying patient. We will then be able to recognize death with the same joy and celebration as we do when we are born from our mother’s womb.

It is my heartfelt impression without contempt that we in healthcare are just beginning to gather our wits and energies in taking the first step towards embracing the need for compassionate, interactive care of the dying and their families.

Countless times in my life, I have stood on fearless, compassionate ground, knowing beyond doubt that the loved one (patient) is beyond all we can offer to heal and cure. I have also watched family members and medical/nursing staff clearly stand in the way of what is inevitably beyond our reach in the human life cycle.

It has been my observation that our own unfinished business about our mortality interferes with this unrelenting dying process of those in our lives and care.

I am certain that there are indeed things so much worse than dying. Scientists go into analysis paralysis frenzy trying to research/discover how to beat the Grim Reaper at his game, without realizing the consequence that their behaviour is at risk of becoming an obscenity for the patient who is dying.

Dying, and how we walk that road, has sometimes only become a greater trail of suffering in our attempts to find that elusive cure. When we, as caregivers, are given the opportunity by necessity to examine our personal belief systems around death, the process of dying will become more humane in our endeavours to comfort in end of life care. We must recognize that cure is sometimes possible, and healing is always possible, if we acknowledge that death can be the greatest healing of all.

Elisabeth Kübler-Ross also taught me something else that helped me, as well as assisted the process for family members of those in my care who were dying. She spoke of how important it is to understand the remarkable power of influence we have in needlessly extending the agony of the dying process for the patient.

Simply by foregoing acceptance of the inevitable, and ‘holding on’ to the dying patient to satisfy our own denial or inability to accept the truth of the events, we can adversely prolong the patient’s lifetime.

Patients, too, wish to resolve their issues with loved ones, and when it is not forthcoming, they wait for loved ones to make peace or forgiveness with their dying. On
many occasions I have watched these remarkable phenomena, and know it to be indeed so. These are simple and profound lessons to be learned from this rich and sacred time, both as loving family members and as health care providers.

If we can open our hearts to our own vulnerabilities, our patients can become profound teachers to our own search for meaning in this life as we watch theirs end. There is so much we can learn from the art of dying with grace and dignity. We need to evaluate our moral distress in a culture where death is regarded primarily as a failure by the health care team.

Technological advances and spiritual and religious questions have unfortunately not led us closer to dealing more graciously with the question of end of life care. Sadly, much of the research and technology has moved us away from the humanism and holism of how we need to approach the dying patient.

In 36 years of nursing practise, I’ve been privileged to care for countless dying patients. My infant daughter’s gift of allowing me to hold her while she died made me an advocate for something I believe strongly is not only possible but necessary: a good death.

Most years, I have gone about my work quietly, and must now beseech with a clarion call to change not only how we approach the dying, but to address the necessity of the subject of spirituality in the instruction and training of our country’s doctors, nurses and other health care professions. It is, in my view, about understanding that spirituality is about regard for our oneness as a human family, without discussion about the divisiveness that often comes about when the topic of religion is introduced. They are not the same subject, although there is obviously a relationship. I believe the apparent confusion about the two has led to reticence in discussion of this in scholarly healthcare institutions in the past. This needs to be rectified if we are to succeed and serve more effectively as caregivers.

In a clear discussion regarding spirituality, there is no right or wrong, no beliefs to challenge. Comfortable acknowledgement of patients’ need to discuss these matters needs to find comfort in our own psyche as caregivers as well.

We must join together and accept the inevitability of our own mortality. At the expense of the innocent, we have worn blinders long enough! My greatest distress is that needless suffering continues to be a part of our healthcare intervention, when the illness is simply ignorance.

We need to refocus from technology and research, and instead roll up our sleeves and dare to embrace the intimacy and holy ground in recognition of what the dying can teach us. We can learn what it means to love enough to surrender our patients to something we ultimately cannot know scientifically or otherwise in this life, and it will not be regarded as failure. Instead, it will be… as it should be.

We must carry this mystery with greater dignity, grace and humility, as something not to be feared but instead respected and expected when all reasonable attempts to sustain life have been surpassed.

My sister’s greatest desire was to leave a legacy that would teach healers about the need and value in dying with dignity, humour, and grace. It is my hope to bring this message to all who care for patients in the home, hospice, palliative care, ICU, long term care or active treatment facilities.
In my first book, *By Grace of Mourning*, I describe the life and death of my infant daughter in the NICU after a month of treatment and heroic interventions. I also describe my healing journey of grief and mourning back from that event, due in part to gifted mentorship by the late Dr. Elisabeth Kübler-Ross, who was world-renowned for her work in the field of death and dying. She taught me how to embrace my grief and grow through it, finding meaning in the madness of mourning. With time, I came to truly appreciate the authenticity and meaning of grace in mourning.

The late Elisabeth Kübler-Ross called this “working through our unfinished business.” When we resolve our fears about death, only then can we fully embrace life.

In a world where we have so much opportunity to care for others, let us offer ourselves the opportunity to examine our personal feelings about our own mortality. Let it be a loving sign of permission to grow if you feel confusion, fear, or reticence around those who are dying. They need you as a present, compassionate caregiver.

Please ask yourself, as my sister did, if you have done all you can to help yourself. We, too, need to listen to our own soul… where the Answer is…