

Being Real with Ourselves

Kenneth A. Bryson, PhD

In the memorable words of Robert Ginsberg, my colleague in value inquiry, “The time has come to turn to the gravest matter, the greatest ruin of them all, that Big Bummer, Death.”¹ The question that strikes me about the “Big Bummer” is that while we stand at the ready to help the dying, what mechanisms do we put in place to help those who deal with the dying?

Let me frame the question from an ethical point of view. The principles of medical ethics, irrespective of what route we take to get to them, always focus on the patient’s best interest. From the Hippocratic Oath to the latest incantation of that oath in the 1980 AMA Code of Ethics, the assertion is unequivocal: let no one enter here who would bring harm to a patient or fail to act on the side of life. The midlevel ethical principles, or those that are halfway between competing ethical claims, are personal autonomy, beneficence, nonmaleficence, and social justice. These principles are fettered by the particulars of the day, as everyone concerned with healthcare costs-benefits their way into providing patients with optimum quality of life. There are times when caregivers seem to be deprived of these same ethical rights, however. The purpose of this essay is to develop a questionnaire to focus on quality of life for caregivers.

A brief review of how the patient’s best interest is served provides an introduction to this topic. The most important characteristic of hospice and palliative care is that it focuses on healing, or what is sometimes called the mind-body connection. To heal someone is to restore them to a functioning degree of unity, even in the face of irreversible cellular disunity. This takes place in the realm of what the founding father of existen-

tialism, Soren Kierkegaard (1813–1855), termed subjective truth. In the 1970s I developed courses on death and dying that borrowed heavily from this view. Pioneer thinkers like Martin Heidegger were among the first to challenge the (objective truth) view of death as being only a technological event.² In that same light, Leo Tolstoy’s (1828–1910) *The Death of Ivan Ilych* tells the story of death as a process of life. Ivan Ilych is a bureaucrat who is more interested in climbing the ladder of success than in developing intimacy with anyone, including his wife. One day a trivial side injury develops into a fatal disease and Ilych learns that he is going to die. His shriek lasts 3 days, but he finally learns the meaning of love. The tragedy of the story is that this is too little too late.

Subjective Truth

The point subjective truth takes out of this exercise is the value of seeing personal death as a process of life rather than as an event that happens someday. Everyone knows that humans are mortal, but the important thing is how we relate to that truth. People like Ivan Ilych get it too late, and others never seem to get it at all; they die poorly and in denial, anger, and despair.

In my classes on death and dying I routinely sentence my students to death so that they can see their own death from the point of view of subjective truth. Why wait for the trivial side injury to develop into a fatal illness? I do not always succeed in this task, however. Some young people think they are invincible and immortal. I ignore this fact and tell them they have 12 hours to live, ask them to write an obituary, and invite them to share with the class how

they intend to spend the last 12 hours of life. Some make fun of the condemnation and condense the next 50 possible years of life into a jam-packed night in which they circle the globe, climb the highest mountain, have children, get high, and party. But those who do get it are more realistic. Perhaps they got it all along. One student reported how a near-death experience changed his life. That sort of experience can transform an otherwise threatening event into a lifelong source of inspiration. Life is short. So the Big Bummer can be more than empirical fact. It becomes the “Big Rush” to live life to the fullest before death. That insight empowers us to make death function as something positive, meaningful, timely, personal, and inspiring.

Spirituality

For this insight to occur one more point has to be added to subjective truth. We enter into a personal relationship with our own death through spirituality. Subjective truth packs a wallop when it arises out of the urgency of a spiritual tendency. If anything characterizes a good death it is the purity of heart that animates spiritual energy. Spirituality has to be plugged into the right kinds of connectors to set fire to subjective truth and transform death from event to source of inspiration. People experience that transformation to varying degrees.

The list of ingredients required for spiritual welding³ includes a mandate to heal (when the search for a cure is no longer possible), subjective truth (not objective truth), death as process (not as event), and the search for appropriate spiritual connections to generate an awareness of belonging to something greater than

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self. The healing practices of hospice and palliative care put these processes in place. One additional point needs to be made about technique before examining how spiritual connections work. The technique I have adopted to initiate spiritual welding is to locate the spiritual and the attendant search for meaning on the arms of the relationships that make us who we are. Structure is a manifestation of underlying processes. Rather than focusing on an elusive structure such as I, self, subject, or ego, it is more useful to work on the processes that generate this structure. Although no one disputes that being human enables us to assess quality of life, the central issue is how we engineer that structure or manipulate the processes that generate quality of life. This view does not reduce the dignity of life to processes but recognizes the role of processes in maintaining that dignity. Human beings are not equally personal. The focus on processes rather than structure provides a practical way to identify the locus of spirituality and meaning in a patient's life. I don't see a patient as a center of interiority who has relationships, but I reverse the order to imagine ways in which I can enliven processes to enhance a structured quality-of-life program.

Levels of Existence

Environmental self

The associations that characterize us take place at three fundamental levels of existence. The first is the environmental self. This route refers to an individual's physical environment or geography of place. The city, street, and house where I live, the building where I work, the room where I am dying, are all part of the environmental self. In the beginning, hereditary characteristics determine environment (e.g., genome, uterus). The self begins as the output of these environmental associations. We can generate quality of life by varying or controlling the environmental associations that give meaning. I include brain chemistry in my list of environmental determinants (thus, pain management).

Social self

A person is also the output of a social stream. The social self arises as a process of nurturing from parents and family, but gradually extends to incorporate

friends and society at large. The social self also includes pets. Quality of life can be impoverished by the absence of significant social relationships.

Internal self

The third arm of this process is the internal self. This is the locus of thoughts, feelings, and processes that are conscious and unconscious alike. Whereas some mental states such as depression can arise as the output of two or more streams of person-making associations, the point is that no self exists in the absence of these associations. The belief in the existence of a separate, walled-in self, or center of interiority is abstract and impractical. The attempt to heal the self without going through the spiritual connections that light up the self is a remnant of Cartesian dualism.

In 2004, I published an article in *Palliative and Supportive Care* that summarizes how meaning clusters around that process.⁴ I described spirituality as a loving tendency toward the sacred (God or higher power). Spirituality as tendency generates our existential restlessness. This restlessness is appeased through the discovery of meaning—a life without meaning is not worth living. Meaning functions as a means rather than an end, however. We continue our search for meaning until we reach the goal of the spiritual tendency, namely, the discovery of God or a higher power. We also can put restlessness on a diet that generates negative emotions. The choice is ours to make. This sets the stage for spiritual welding.

Sharing Our Stories

I have hypothesized that the processes that generate structure (the self) provide a road map to what it means to be a human being. We can use these pathways to deliver quality health care. In the beginning, hospice and palliative care staff can use the person-making process as a way to identify gaps in patients' lives. These gaps arise at places along the arms of the person-making process where meaning is lost due to illness. For instance, the bedridden patient is away from home and work, away from family and friends, and quite naturally distressed or depressed. This technique affords us a very practical, direct way of determining

the exact particulars of the case.

How do we identify which processes are most significant to someone? We ask. We invite discourse about these associations. First we need to earn a patient's trust, which we can accomplish by risking something of ourselves and sharing stories about our own associations. We can use these stories as a bridge to the suffering of others (compassion). Resonance and identification generate a shared comfort zone as we share private stories of triumph and defeat. This does not mean that every patient needs to find meaning from the experience of dying, but that meaning displaced by the experience of dying has to be replaced. The patient is restless in the absence of this sort of spiritual weld-

ing. Storytelling allows us to identify the exact place of meaning by locating holes or places of emptiness in the person-making profile. Once these gaps are identified they are spot-welded with fresh meaning. The creation of fresh associations allows the patient to make sense of the dying experience. Depression and negative emotions can rise to fill unintended gaps. Our existential restlessness is a consequence of being spiritual. Depression provides notice that our existential restlessness was put on a bad diet. The solution to restlessness is to spot-weld the space left behind by the loss of meaning. These new associations are designed to promote movement toward transcendence. Sometimes this is done one baby step at a time. We can begin with the

discovery of a source greater than self.

My own need to face the Big Bummer was brought home to me when one of my students, Nancy, died. My student was ready for personal death, as I am for my own death, but I was not ready for her death. Nancy was a very bright, articulate, loving person. She reminds me why I entered the teaching profession—always eager to learn, read, share, discuss, and always with an open mind. Nancy's reaction to the classroom death condemnation was very direct, open, and realistic. She was very comfortable with the idea of subjective truth and told the class that her affairs were in order and that she did not fear death. She wrote an obituary the way

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Spiritual Welding for Caregivers

The following questions suggest ways in which the person-making process can be checked for gaps or restlessness gone sour. The questions are best used in an environment designed like a self-help group for caregivers. There answers will reveal gaps that identify places where existential restlessness needs to be filled. The goal of spiritual welding is to identify these places and begin the process of generating new meaning. I have not discussed the role of complementary therapies such as art, music, dance, and painting, but the only limit on spiritual welding is the creativity of a welder. I wish to thank my nursing students at Cape Breton University for helping me to frame these questions."

Questions Concerning the Environmental Self

How is the hospital environment supportive?
Do I have a happy space where I can go for healing?
Do I have any unfinished tasks at home nagging me?
Do I find meaning in nature?
What meaning do I find in nature (God, higher power, peace)?
What do I like most about nature (hills, ocean, grass, smells, wind, and rain)?
Do I use my environmental connections as a source of healing?
Do I have a green life (plants, garden, trees or shrubs)?
Do I have any hobbies?
When was my last vacation?
Have I taken time to gaze at the night sky?
When was the last time I had a bubble bath?
Do I take time to go for drives?
Should I transfer to a different area of health care?
Is there anything else in this category?

Questions Concerning the Social Self

What relationships are most important to me?
Do I have the support of my church community?
Is my family supportive?
Are my colleagues and friends supportive?

Do I harbor resentments toward anyone?
Do I need to make peace with anyone?
Do I take time to play with my pet, walk the dog, cuddle the cat, and talk to my parrot or goldfish?
Do I have the support of my patient's family?
Do I belong to a support group (church community, 12-step program, other)?
Am I making use of my social connections as a source of healing?
Do I accept help when it is offered?
Is there anything else in this category?

Questions Concerning the Inner Self

Am I at peace (mind-body integration)?
What gives my life meaning?
What values and beliefs are most important in my life?
How do I feel about myself (at peace or anxious)?
How do I feel about my work?
Do I feel like I am making a difference?
Can I recognize when I am feeling stressed?
How does the death of my patient or friend change the way I find meaning in life?
Do I feel connected to God or a higher power?
Can I share my feelings with others on this team, or do I keep them bottled up?
How do I cope with my losses?
Do I feel that I was honest and open with my patient?
Do I wish I had done more for my patient?
Am I making use of quiet time, prayer, meditation, breathing, and relaxation as a source of healing?
Do I journal my feelings?
When was the last time I had a good cry?
Can I use the arts (music, theater, drama, and painting) as a healing conduit?
Do I count my blessings everyday?
Is there anything else in this category?

she wanted it to appear in the newspapers. The details of how she would spend the next 12 hours of life were not changed by my death sentence. Nancy was not phased because she accepts death as being an integral part of her being, not something “out there” that happens to the impersonal “they” someday.

Nancy graduated and I did not see her for a couple of years. Then I heard that she had been very sick. One day when I was at the hospital for a meeting, a staff member informed me that Nancy was in palliative care and wanted to see me. Sadly, I reacted in objective truth—I said thank you and kept walking. She died a few days later. I regretted not making the effort to spend time with her. If she had asked me to develop a theorem or discuss the metaphysical foundations of the epistemological paradox in Emile Meyerson’s philosophy of mind, I would have been there. But I wasn’t ready for Nancy’s dying. I taught her objective truth, but she offered me subjective truth and unfortunately I couldn’t handle it. I would be Professor, Sir, or Doctor, but no one would call me a spiritual welder that day. The literature suggests that being (or not being) with the dying is always a profound emotional experience, one that reason does not control.

Supporting Caregivers

Martha Holstein’s article “Facing Death: An Essay on Susan” (2002) reminds me that hospice and palliative care workers need a support system.⁵ Holstein tells a poignant story of Susan’s dying. She wonders if they could have been more open with the patient. Holstein says that caregivers did not have a problem

being straightforward with Susan, but that Susan did not want to be identified with her disease. Susan presented as a bright, articulate, strong-willed person. She did not choose to find meaning in her dying experience. She focused on maintaining a sense of personal identity in the face of death. While Holstein worried about Susan’s death (i.e., whether it was a good death or a bad death), I wonder what mechanisms exist to support caregivers. Can I be fully autonomous and beneficent if I am unsure of what the patient wants? What mechanisms are available to discuss these feelings? How do caregivers cope with the death of a patient? The solution to this dilemma calls for a look at the caregiver’s spiritual profile.

How do we do for ourselves what we do for others? Years ago I found an excellent reminder of subjectivity in Robert Kavanaugh’s book *Facing Death* (1972).⁶ He explains that the first step in being real is permitting personal feelings to be honestly and fully felt. This is subjective truth. Spiritual welding and healing is not about what we can understand about death but how we relate to it. That focus transforms an otherwise impersonal event into a meaningful process. Spirituality springs to life on the arms of person-making as our existential restlessness connects with a source of meaning. Spiritual welding arises as the attempt to weld fresh connections whenever the meaning of life is lost or threatened by dying and grief. The questionnaire (p. 3) is designed to help caregivers assess their own spirituality as they cope with the death of others.

Hospice and palliative care teams can meet on a regular basis to conduct this caregiver inventory. Separate meetings can be held to discuss patient needs. We need to help ourselves so that we can continue to help others face death. This need goes beyond the subjective acceptance of our own dying—though this is certainly a prerequisite to helping others—to focus on how the death of others affects us. We need to take a spiritual inventory of meaning in our own lives. The person-making process can help us in that regard. An honest and open discussion of these issues in a receptive, nonjudgmental environment will help us to accomplish that objective. The process of conducting a rigorous spiritual inventory of our feelings locates places of displaced meaning in our life and shows us where adjustments are needed. The process is like opening a window and letting in fresh, spiritual air. ☺

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