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BRINGING DEATH TO LIFE: TRANSPERSONAL CARE OF THE DYING

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*Like the rising and setting
of the sun and moon,
Composite things are impermanent.
The time of death lies uncertain,
like a flash of lightning in the sky.*

—Padmasambhava

Most individuals have some memory of childhood that is linked with death. When I was in the third grade my grandfather died and people treated me differently for a few days, like I was special and somehow set apart. Even Mom and Dad talked about the death in hushed fearful tones, which seemed especially unusual to me since they were often fighting in loud angry voices. Death seemed to change people. At granddaddy's funeral I saw a hearse for the first time—the one with his coffin. It looked just like a limousine to me. I was confused because most of the grandparents I knew were already being driven everywhere in limousines. No one talked about the death. Because of the way others were responding to it, death became a terrifying and unspeakable event to me.

When I was in college, my boyfriend David was killed in an airplane crash, and it was only because of a last minute change of plans that I was not with him. No one wanted to talk about it, or to let me talk about it. Distraction, small-talk, and entertainment suddenly appeared when a reference was made to death and loss. When I tried to talk about it, my sorority sisters told me I was getting morbid. Then my younger sister, newly married and eight months pregnant, suddenly died. I was stunned. My family was stricken with the silent, angry pain that seems to accompany a lack of forgiveness. My father said with conviction: "There is only one question to ask: Why us?" It is clear to me now that my family's uneducated response to death was rooted in a widely accepted cultural attitude towards death—denial.

Weisman (1972) outlined some of the most popular cultural misconceptions about death and dying: (1) No one wants to die unless they are suicidal or psychotic; (2) preparation for death and reconciliation with death aren't possible, so when one is with a dying person, the best course of action is to say as little as possible and avoid all issues relating to death; (3) people who are dying do not really want to know they are dying. If they did, they would ask more questions. It is risky to get involved in a conversation about death because it might precipitate a mental depression; and, (4) after everything has been done medically to treat the person, he or she should be left alone as much as possible. The person will then withdraw and die in peace. Misconceptions such as these are the framework for much of the isolation and abandonment that the dying often experience in our culture.

In a New York inner-city emergency room I learned graphically, as a nurse, about the triumph of saving life and about the failure of death. The diversity of events transpiring there, both tragic and comic, were alike in one way—they were transient, arising and diffusing so quickly, and with such urgency, that normal chronological time ceased to exist. Some days, death would permeate the air with a thick, eerie, presence. Every person who died there was different, each had a unique story, and yet, ultimately, each shared a common fate. The

struggle for survival overshadows death: medical treatment has failed when death occurs, and failure is not welcome (Becker, 1973; Bowker, 1991; Kastenbaum & Aisenberg, 1976).

A day in the emergency room may begin slowly but events can erupt with intense drama at any time. A mother runs into the area with a motionless baby that she has discovered dead in its crib. The mother is overcome with dread and disbelief. It is a sad and dreadful experience that shocks everyone. Enshrouding the tiny corpse is a gloomy task. Soon after a small boy is wheeled into the trauma room. He has been savagely kicked and beaten by his alcoholic step-father. Futile heroics fail to rescue him; the boy's tiny, bruised corpse looks translucent and ethereal—lying poised on the gurney—dead. The tempo in the emergency room is urgent and driving. It is compelling to postpone thinking about the meaning of death and loss, at least for the moment.

The death of two children in one day is always difficult to understand, but three made it almost unbearable. Later in the same day, a teenager, just stabbed to death, was rolled through the ambulance entrance by fleeing gang members. A beeper, hanging from his torn and bloody belt, sporadically paged him throughout the frantic resuscitation effort; sometimes the world can seem very futile. The worst case for me that day was the resuscitation of an emaciated, ninety-five-year-old woman. I heard her ribs breaking with load cracks beneath the cardiac compressions. Finally revived, she lay confused, wild-eyed and in agony . . . and then died amidst a jumble of tubes, needles, masks, and shouting caregivers. This woman's death scared me the most.

Emergency room patients bring with them an unusual sense of tenuousness and uncertainty. The situation is fraught with the impermanence of life. It is their impermanence, though. As a nurse, however, it is just another "permanent" workday—average. Circumstances in the emergency room are unpredictable and, even amidst the death, life continues to pulsate there. Though death is a profoundly disquieting event, other dramas could also be disturbing. By modeling the seasoned caregivers, I too learned how to appear reactionless—even in the most traumatic and unusual cases. Most of the emergency room caregivers I worked with had repressed fears about the inevitability of death and loss. Then there were times when the ongoing attitude of impassive indifference could change to one of unrestrained uproariousness.

One day a disheveled mother and her screaming, overweight daughter burst into the triage room. The mother looked confused and defiant, and shoving her daughter forward announced, "This here's got the apen-dex. She be sick at dinner, she got to have some doctorin', she got the bad, intestaments problem."

Helping the girl to sit down, I asked the routine question "When was your last menstrual period?" The mother became angry. She yelled "That ain't no kinda question to be askin' her, I already done told you what she got; don't you be talkin' no monthly time." The girl fell over moaning and clutching herself tightly. As we hoisted her onto an examining table, her contractions were coming faster. The mother became increasingly belligerent and distraught, and repeated with emphasis, "She ain't neva, evah, been with no damn man! She too young for that garbage." The doctor eased the newborn out onto the table and the daughter's screams subsided. There was a hushed pregnant moment. The daughter turned her stunned and horrified face from the baby to her mother and back, and then, pointing at the baby and looking at us, she cried out with the same kind of righteous emphasis as her mother used, "I can tell you one thing for sure, that ain't mine."

Later, we caregivers recalled the tragic incidence of denial as one of the most hilarious we had ever experienced. Even though there was nothing funny about the stark reality of the event, from then on we repeated the phrase "I can tell you one thing for sure, that ain't mine"

in many different situations, time after time. My own terror and denial of uncertainty, change, or death was not apparent to me.

When I first started working as an emergency room nurse, the drama of human life that flows so deeply there could easily flood my feelings. But personalizing the constant experiential onslaught exhausted me deeply, and I adopted a more conventional, superficial attitude, one that soon developed into impassive denial. The emergency room mirrors a transience that is difficult to accept: life is fleeting and any one of us could die at any moment. Many caregivers choose to postpone facing this discouraging reality. It is easier to deny feelings and thoughts about mortality than it is to explore personal reactions and beliefs about death and dying—especially when the denial has been preceded by little or no education about death and methods for coping with it.

Recently I took my 11-year old nephew, Joe, to an emergency room in California after he had severely cut his hand while opening a can. The tendons at the base of his thumb were exposed and a small torn artery was pulsing blood. He was scared. Joe and I had been together years earlier during his father's lingering illness and death at home, but he had never wanted to talk about it. I said, "You probably are wondering if you could bleed to death. You won't. What do you think it means to die?" He thought for a moment and said, "It means that I would miss football practice."

I held his arm upright as we hurried into the emergency room and were stopped at the patient-registration desk. With bored looks the nurse and others prodded me with questions about insurance, guardianship, medical authorization, consent to treat, relationship, and other legalities. No one offered Joe a chair, an ice bag, a clean dressing, a drink of water, a blood pressure check, or any other assistance. No one there spoke to Joe. It was not a pleasant social or medical experience, yet those masks of impassive denial looked all too familiar to me.

Generally, people seem captivated by the intense emotional feelings that arise from imminent death and loss—as long as they are experienced from a distance. Dramatic and death-ridden emergency room stories seem to fascinate people. So do highway accidents, and other second-hand disasters—events that happen to others. But, when such dark circumstances strike personal ground, intrigue can quickly turn to denial.

Most individuals in the West have learned denial as a primary coping mechanism, but there are other, more useful ways to respond to death and dying. To learn these effective strategies for reacting to death, however, requires an exploration into personal constructs about mortality: It is a process that most people are conditioned to avoid. To develop more creative responses in interacting with death and dying requires self-awareness about the meaning of the feelings that arise when facing a dying person (Attig, 1995; Bertman, 1991; Buckman, 1992). Gaining self-awareness will tend to increase understanding and thus broaden the number of possible creative responses (Corr & Corr, 1994; Feinstein & Mayo, 1993; Kastenbaum, 1992).

My fascination with the emergency room diminished gradually. I became less able to deny the psychological impact of the events that occurred there. Certain incidents began to emerge and catalyze a deeper contemplation of my work environment. One situation in particular marked the beginning of a profound change in my attitude towards life and death. It was after an obstetrical case where the OB/GYN resident had scraped the uterus of a young pregnant woman who was having profuse vaginal bleeding. It had been a bloody and painful miscarriage. I never saw the patient again, but as I collected the used instruments strewn around the room, I was shocked as I bent over to pick up some forceps. There, in a pool of liquid, lay a gelatinous, round, opaque, flesh colored embryo—a tiny circular shape of an

emergent human being, dead in its encasement. I put it carefully into an emesis basin and felt rage at the indifference that had been exhibited toward an emerging life. I asked myself, "At what point is value placed on a life? How could this small being be discarded as tissue?"

Only weeks after the embryo incident, my brother Wheeler telephoned to say he had a tumor growing around his aorta, and "they" deemed it malignant until proven otherwise. I was stunned. Suddenly I was being forced to evaluate my own constructs about death and the meaning of life much closer to home. Wheeler and I had been together throughout much of our lives. At times our relationship had been full of turmoil, but during his dying trajectory we were drawn together in a way that would forever change my life. Though his cancer had been pronounced inoperable and untreatable, he chose to deny the terminal aspect of his metastatic carcinoma until just weeks before he died. Wheeler had never been religious, but he was spiritual, and he was asking me for help.

After working in emergency rooms for ten years, I began hospice nursing. My caseload was twelve young gay men who were dying of AIDS. Working with them introduced me to a new subculture and brought to my recognition the vast expanse of the HIV epidemic, about which I had known very little. Over the next year I became friends with each of these twelve men; and I was present when many of them died. As a professional caregiver, I realized all too well the limits of my knowledge about interacting effectively with dying patients.

Unlike emergency room nursing, hospice nursing required a deeper presence, for long periods of time. The emergency room habits of hurrying, assuaging, assuring, and ignoring were not appropriate in the hospice setting. In the emergency room, the focus was on formulating immediate solutions to urgent situations and actual occurrences; in hospice care the focus was on the patient and on creating a harmonious environment. I had to quickly reeducate myself. My emergency room habit of doing the same task over and over was not appropriate in the hospice situation.

Being with the dying brings about an awareness that each day could be the last—a realization that serves as a powerful antidote to superficial chatter and pretentious interaction (Backer, Hannon, & Gregg, 1994; Callanan & Kelley, 1993). Continuing meaningful interaction was required as I lived through the dying of many of my AIDS patients. And the death of patients with whom I had developed a bond made it less possible for me to deny the inevitability of death. Death is final—what has gone before no longer exists, and what is to come is only a fantasy. Tangibly experiencing the inevitability of death on a daily basis, despite preconceived ideas about longevity, began to transform my life. Habitual, mundane activity gave birth to a greater awareness of the importance of being present in the moment.

The death of a friend or someone we know is an existentially compelling reminder of impermanence. It shocks some of our cherished beliefs about the nature of the self and the world. We tend to believe that the world is relatively fixed, unchanging, and controllable, but when a friend dies, our tidy view of permanence is called into question. When facing the stark reality of a death, wishful beliefs about immortality lose validity, and feelings of helplessness, hopelessness, and quintessential emotional pain can arise (Axelrod, 1987; Weisman, 1980; White, 1988). Yet, the very state of crisis that a death evokes, also tends to deepen, in more positive ways, an understanding of death, and more broadly, a recognition of the changeable, impermanent nature of conventional, constructed reality.

While I was in Nursing School in San Francisco, my closest friend Julie was in an automobile accident. Her spinal cord was permanently severed. She was paralyzed from the neck down. Julie's family was able to provide her with whatever physical assistance she needed. They added a huge suite and handicap bathroom to their spacious home in Marin County and hired full-time nurses. Julie continued to live there for a few years, during which she discovered

the meaning of her newly imposed limitations. At her request, I lived there too, and commuted to nursing school. Years later my husband and I built a studio addition to our house in Aptos so that Julie could live with or visit us and our children whenever she wished. She came often during the period when her physical condition was still strong.

A few years after her last visit, Julie's brother Henry called me to say that Julie was "drifting away." I was shocked and said, "What do you mean by drifting away?" He told me that she was losing her battle with the bladder cancer that had plagued her for the past two years. He also said that she had asked for me, and that I ought to come to see her that night. It was difficult for me to say that I would go. "What a depressing task," I thought, "Such a long drive, I wouldn't get there until late tonight, and what will I say to her anyway? I can't stand to watch her die. What if she died right while I was there, what would I do? I am supposed to know what to do around death, but I don't. I hate death." I tried to sleep that night, restlessly tossing under the quilt of denial I had neatly woven out of excuses and rationalizations. At six in the morning I called her. Henry answered and said that the mortuary had taken her body away just an hour ago. "She died?" I gasped, "I will be right there."

Driving across the Golden Gate Bridge to the mortuary that morning, I remembered the wonderful apartment on Telegraph Hill that we had once shared with two other girls. We had all been in prep school together and then became sorority sisters at UC Berkeley. Our social lives were primarily focused on parties, dating, clothes, and marriage. We did not seriously consider the fact that death could be part of any one of our lives. Now, ten years later, Julie was dead. I wondered why I hadn't rushed to see her yesterday while she was still alive. Instead I was rushing to see her now, after she had already died.

Having received permission from Julie's mom to view the corpse, I was waiting nervously in a special room of the mortuary. I heard the clanging of metal and then the door opened. I stood up as the mortician wheeled in the gurney holding Julie's draped body. After he left, I cautiously pulled the sheet away from her motionless face. Her eyes were half shut. They looked cloudy and dry. Her last breath seemed to still linger and hang almost audibly in the set of her mouth, the slack of her jaw. I fought to keep from crying, and my throat was constricting in pain. Leaning over and gazing at her, I saw tears from my eyes hit the blue-white granite of her stone cheek and smoothly roll, like raindrops down a statue, to the sheet below. I stood there transfixed.

Being with Julie in death like that transported me for the first time to a space beyond the confines of my own conventional thinking. I realized that the pain and sorrow gripping my chest as I looked at her corpse was related to my own sense of loss and deep remorse about having avoided her when she was dying. She, however, was finally freed from physical boundaries and the paralysis that had kept her locked in one position for so long. I felt her presence in the room. She was there, I sensed, but no longer a part of the silent corpse that used to be "Julie." I kissed her ice-cold lips, and I thanked her for teaching me so much about friendship, love, and the uncertainty and constant changing nature of life. After I left her presence, the unusual and exhilarating sense of liberation I had felt during the experience soon faded.

Years later, after encountering the death of many other people, I came to understand the sense of liberation I had felt during my experience with Julie. For me, being in the presence of death catalyzed the emergence of an expanded view of the world and a recognition of the ceaseless transformations of existence. Death taught me about my own impermanence, the uncertainty of life's circumstances, and the futility of clinging to situations inevitably destined to change. It was an attitude that seemed to free me somewhat of death anxiety and fear, at least temporarily.

There are studies that suggest cultivating a more educated attitude about death reduces the anxiety and fear of death that many patients and caregivers experience (Lonetto & Templer, 1986; Neimeyer, 1994; Stoller, 1980). It appears that accepting the inevitability and the naturalness of dying and death may offer strength and consolation to both patients and caregivers, and promote open-minded interaction with one another.

Death education must also address the potential transpersonal dimension of dying. The dying trajectory is sometimes accompanied by unusual phenomena that cannot be easily explained using existing Western paradigms (e.g., the near-death experience, deathbed visions, and transpersonal insights). A lack of understanding about these events can impoverish interaction, lead to a sense of isolation for both the patient and the caregiver, and arrest or dissipate transpersonal experiences of the dying. Practical models of competent and compassionate communication need to be further developed and expanded to include events that lie beyond ordinary concepts of states of consciousness. Transpersonal concepts are now sometimes recognizable in hospice care and training, but the need continues for a still broader and more widespread transpersonal vision in death education and care of the dying.

Because of the ground-breaking work of Kübler-Ross (1969, 1975, 1981) and the subsequent introduction of hospice ideology, more individuals are now able to choose palliative care for themselves, rather than the traditional aggressive medical treatment for terminal illness. Unshrouded by the life-saving paraphernalia that usually surround a dying person in the hospital, the hospice patient today faces the caregiver more freely and more frequently, necessitating genuine communication and compassion—including more openness to the transpersonal dimension.

The number of in-bed hospices continues to grow today, and more so than ever, caregivers are required to interact with dying patients for longer periods and in more intimate and meaningful ways. Practical models of competent and compassionate communication and understanding need to be developed to accommodate this changing environment of the patient and caregiver and their relationship.

An expanded transpersonal dimension in hospice care and training can enrich understanding of the dying trajectory for both caregivers and patients. Most traditional models of death education (such as those offered in nursing and medical schools) do not provide a means for the development of a genuine and truthful attitude about death. To ensure meaningful interaction, it is imperative that death attitudes and death education be expanded, including confrontation with mortality and an understanding of the transpersonal dimension.

* * *

When I began my career as a nurse and was exposed to death and the dying on a daily basis in the emergency room, my initial underlying attitude of death denial matched that of most professionals. Death was not accepted as a part of life. Lack of death awareness was the norm, and seemed natural. Habitually denying death, and maintaining relatively superficial interactions with the dying, continues to be a model of behavior many caregivers find agreeable and convenient. Eventually, daily contact with emergency room tragedies radically shifted my beliefs. Then, my later career as a hospice nurse revealed to me a broader, more transpersonal view. Now, if I am receptive and undistracted when interacting with a dying patient, I can experience the exchange to be deeper and more genuine. Today, my patients and I learn from one another.

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