



The Nature and Treatment of Human Suffering

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The major problem with our current social structure is the apparent inability to understand the nature of suffering. Suffering is an interrelated system of thoughts and emotions far more complicated than physical pain alone. Suffering involves a complex mix of the spiritual, mental, emotional and physical components that completes a human being.

At Calvary Hospital in the Bronx, New York, the unremitting goal is to relieve suffering in all its faces. Calvary is the only fully accredited, acute care hospital in the U.S. devoted exclusively to the palliative care of adult patients with life-limiting illnesses and advanced cancers. Approximately 2,500 cancer patients are admitted each year. Almost all are suffering from wasting due to their incurable condition.

The average length of stay is 25 days. More than 90 percent of these patients die, robbed of their aspirations and futures. Tumors have stolen their lungs, disfigured their faces, silenced their voices, broken their bones and paralyzed their extremities. Many have been rendered hairless, wasted, helpless, dependent and bedridden. Often they vomit, bleed, swell and become deformed.

By its mission, Calvary Hospital sees in every suffering patient a supreme dignity, even in the confines of a decaying body. Patients and their families never are abandoned. Never do they feel the absence of love.

END-OF-LIFE CARE

In recent years, a concept of end-of-life care has developed into a medical specialty to ameliorate the human suffering associated with intolerable and unacceptable symptoms. People tend to call this palliative care or hospice care — they use the terms interchangeably, but that's not exactly cor-

rect. Hospice care is associated more frequently with home care for a patient nearing the end of life but whose symptoms, despite their severity, are reasonably stable and do not require the continued daily presence of professional medical staff to treat them.

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Palliative care, on the other hand, refers to treating patients whose symptoms are both unacceptable and unstable — such as seizures, gastrointestinal obstruction, severe difficulty breathing (dyspnea), etc. Palliative therapy at the end of life requires professional, continuous presence by doctors and staff.

In the context of end-of-life care, both focus on recognizing and addressing the multiple components of human suffering, the first of which is:

Spiritual Pain. The seminal questions confronting all of us with end-of-life issues have to do with the presence of a supreme being, God. We ask, "If there is a God, why has he chosen me to

die at this time? Why now? Is there a heaven? Or is there a place of suffering, hell? Am I being punished for some deserved reason, which includes ill deeds? Will I be no more, will there be any sign or mark showing that I passed this way?"

Mental Suffering. Calvary Hospital, through its Palliative Care Institute, sponsors an active psycho-oncology department of patient care overseen by a director of psychiatry. Mental suffering, though scarcely ever mentioned, is an overwhelming aspect of human suffering in end-of-life issues. Expert psychiatric care can confront and, for the most part, control or even ameliorate these three diagnoses of mental suffering:

- Delirium is, by far, the most common diagnosis found in end-of-life patients. During the course of the primary diagnosis, approximately 85 percent of patients develop some form of delirium, which is characterized by the sudden and progressive loss of cognitive faculties over a relatively short period of time.

Delirium is described by patients as being in a deep, dark, pit filled with offending creatures or plagued with large insects over the torso. Of particular terror is the appearance of medical staff with human bodies and animal heads. Untreated delirium in final stages almost always slides into violence propelled by hallucinations. For only very short periods of time, and after all other avenues have been exhausted, are restraints used for patient control. The patient is never unattended and is quickly unfettered.

- Depression is the second significant psychological diagnosis in palliative care, and it is most often confused with sadness. Depression is the most potent affective disorder that changes the life force in our patients. In general, manifestations of pleasure are absent or greatly diminished. Unless treated, depression becomes intractable or greatly resistant to therapy.

- Panic Attacks/Agitation are the third major psychiatric syndrome affecting end-of-life patients. They take the form of periodic bouts of "flood episodes" — bouts of extreme terror, manifested by fear and grief associated with agonal cries for help — desire to flee, secreting oneself from others and exaggerated physiologic responses such as terror responses, tachycardia, dyspnea, hyperventila-

tion and other untoward psychiatric manifestations of cerebral dysfunction. With treatment, panic behavior generally has a positive outcome.

Emotional Suffering is a significant and important aspect of human suffering. If one aspect of palliative care could be defined as the seminal event, it would be emotional pain, with its feeling of abandonment. One feels abandoned by hope, all human love, one's own body, medicine and, finally, God.

Recognizing and treating emotional suffering is what defines Calvary Hospital. Neither sympathy nor empathy are sufficient, they do not satisfy the needs of fractured patients. Only love is enough. We must approach them and give them an abundance of love.

Here are major ways to manifest love:

Presence, which means see your patient as scheduled and promised. Promises must be kept. If delayed, message your patient by phone or person or friend.

Touch, because human beings are tactile creatures. Hold your patient's hands or feet. Stroke the body, forehead, etc. Hold the patient; gently grasp your patient with your arms around the head; stroke the arms, pat the cheeks.

Speak. Speech is a spiritual event given to humans as gifts. God has no arms or legs. You become his presence, your hands become His

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hands, your legs become His legs, and they take you to the patient's room. And you become the voice of our Father. Use language such as "I love you. I will hold you tight. Dear patient."

Create a sanctuary. Upon entering a patient's room, always pause for a silent meditation. Speak from your heart, entitling the space, something as simple as this: "Dear Master of the universe, I am your arms and legs. Please make this a holy room, a sanctuary."



Physical Suffering is the fourth aspect of human suffering. There are myriad methods and pharmacological approaches to controlling a patient's pain. However dyspnea — difficulty in breathing — frequently is mentioned only in passing, though it is analogous to chronic suffocation. There is hardly any symptom more unbearable for patient, family and staff, and a majority of patients suffer from it in the last six weeks of life.

Dyspnea is air hunger. The last three patients referred to Calvary Hospital from a major referral center arrived suffering from severe, unacceptable dyspnea. They were accompanied by a family distraught by the sight and sounds of a beloved person for whom pain was never an issue, but the breathlessness was unbearable. All measures should be employed to control this most noxious of all symptoms.

Speaking of family, no aspect of palliative care is more difficult and stressful than the interaction of family and staff. In their pain and helplessness at their loved one's plight, the family almost always holds a presumption of neglect on the part of staff. For the staff, contending with a family's suffering actually can exhaust personnel and destabilize their health. The answer at Calvary Hospital has been to establish a Department of Family Care to help patients' family members and to improve communication.

Grief endures our whole life. It is relentless and appears at all meaningful events to remind us of our loss. During periods of small pleasures, there is a knock at our door. We answer and find two persons in long, somber, leather coats standing there. They speak: "Hello, We are Mr. Grief and Mr. Guilt. We want you to know that we are always here to remind you, in a word or a song or laughter. Always, we are here."

ASSISTED SUICIDE

Nationally, health care has taken on both a political and an economic urgency to adopt cost-saving measures, especially at the end of life where medial expenditures may escalate rapidly. Independent health insurance plans and managed-care payers have great reluctance to allocate funds for advanced cancer when therapy is considered

symptomatic and palliative.

However, the control of suffering is not an economical event. It requires professional and paraprofessional staff, along with the complex administration of drugs and preventive measures to preclude a painful and protracted clinical course.

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Frustration and failure in reducing health care costs, along with society's abandonment of the suffering, incurable patient, have prompted active discussion of physician-assisted suicide. In certain public arenas, so-called death with dignity measures have been adopted. Of greater concern may be the implicit assent by some legislative bodies.

Physician-based and controlled assisted suicide is an ultimate cost-saving measure. That means across the land, in our homes and our nursing homes, in minivans, cellars, trailers and even reverently in our churches, physician-assisted suicide with governmental consent could become a legal cost-saving health care policy. The solutions they offer are expedient or over-simplified with reasons falsely clothed in the moral platitudes of mercy, choice and dignity.

I read with despair the finding that placing a nozzle over the exhaust system of an automobile and pumping carbon monoxide into a patient's lungs is a form of compassionate medical therapy for incurable disease, as long as it is requested by the suffering recipient.

By that way of thinking, Calvary Hospital should be besieged with such requests, considering our patients' terminal clinical afflictions. Yet, neither are we asked to assist in suicide, nor do our patients despair.

At Calvary Hospital, there is a scientific and human alternative to the organized, cooperative,



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final exit of incurably ill cancer victims. They never are abandoned. Never do they feel the absence of love, and never have our patients asked for physician-assisted suicide.

When the discussion of medical care in terminal illness involves physical symptoms alone, the entire notion of suffering is confounded. Suffering involves much more than physical pain. The physical aspects of pain are rapidly and effectively controlled by a skilled staff of physicians and nurses. We have no problem controlling physical pain.

Spiritual pain begs for the connection of man to God and God to man. Mental pain involves anxiety, agitation, sadness, depression and even confusion and delirium.

Emotional pain is, indeed, the most resistant form of suffering, and it can be treated only by other humans who are committed to be the physi-

cal presence at the bedside. Emotional pain begs for the presence of other feeling people. Emotional pain involves the final farewell to spouses, families and friends; the recognition that a life may be unfulfilled; the knowledge that children will not be seen to adulthood; that grandchildren will never be known.

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It is during these periods that victims may ask for assisted suicide. Only immersion of our patients in a sea of love can control the emotional pain. We simply hold, caress, nurture and surrender to our patients all that we humans can give to another. Indeed, we wait with them in the vestibule of heaven and let go when a love greater than our own pulls them free.

Calvary Hospital exists in New York as a living, magnificent monument to physicians and nurses and all caregivers treating patients who need them the most when they would suffer the greatest. We are a scientific and social experiment that answers one of the most pressing issues of our time.

Indeed, we are a treasure in the health care system. Now we also may be the beacon for a collapsing moral system.

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