

Dancing With Broken Bones



Race, Poverty, and Dying in Urban America

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Musings On Healing And The Human Spirit

“...for the secret of caring for the patient is in caring for the patient.”

- Frances Weld Peabody

“Nursing would be a dream job if there were no doctors.”

-Gerhard Kocher

“For of the most high cometh healing.”

-Ecclesiasticus

“Ease his pain... go the distance.”

-WP Kinsella, Shoeless Joe
- Field of Dreams (the movie)

“When you come to a fork in the road, take it.”

-Yogi Berra (20th Century Philosopher)

“Physician, heal thyself.”

-Luke 4:23

“Clinical competence must include not only mastery of science but appreciation of the personal and social needs of the patient.”

-Albert R. Jonsen

The New Medicine & The Old Ethics

“God heals and the doctor takes the fees.”

-Benjamin Franklin

“Two roads diverged in a wood, and I... I took the one less traveled by-- And that has made all the difference.”

-Robert Frost

“The trained nurse has become one of the greatest blessings of humanity, taking a place beside the physician and the priest.”

-Sir William Osler

“Build it... and they will come.”

-WP Kinsella, Shoeless Joe
-Field of Dreams (the movie)

“The art of medicine consists of amusing the patient while Nature cures the disease.”

-Voltaire

“The poor, I do not tire of repeating this, are wonderful.”

-Mother Teresa

“There is a balm in Gilead To make the wounded whole.”

-African American Spiritual

Mindful Listening: Patients as Teachers



“God makes all this possible. Yup He does.”
-Cowboy

Lessons from Cowboy: Traditional Ethical Principles

- **Justice**—Harm of poverty and racism
- **Non-Maleficence**—Absence of compassionate care creates harm (ICU, ED); spiritual isolation
- **Benevolence**—Palliative care team committed to “going the distance”
- **Autonomy**—Understood and respected as an individual by palliative care team and student-physician caregivers

Lessons from Cowboy: Toward Social and Cultural Understanding

Cowboy’s life experience was largely shaped by the injuries of poverty and racism. Despite their deleterious impact on his mind and spirit, he developed remarkable resiliency in life— a strength that became part and parcel of how he responded to being sick. Understanding Cowboy’s complex background, and who he was as a person, helped caregivers to provide exemplary person-centered care. Appreciation of his personal history helped caregivers stay committed to him throughout his illness.



"It's so hard to watch him lay there like that."

-Virble

Lessons from Kenny and Virble Miller: Traditional Ethical Principles

- **Justice**—Hardships of poverty; inadequate access to care
- **Non-Maleficence**—Suffered pervasive indignity from negligent care; poor communication
- **Autonomy**—Choices not honored

Lessons from the Millers: Toward Cultural and Social Understanding

In order to understand the Millers, it is critical to appreciate how the daily grind of living in poverty shaped their spirit of independence and capacity for hardiness. They toiled hard throughout their lives to raise their family, "doing it their way." As they faced their respective illness experiences, it was important for them to have their wishes honored and dignity preserved. Poor communication and inadequate patient-centered understandings in oncology clinic led to clinical decisions that did not serve Mr. Miller well. Lack of compassion for their tribulations led to exacerbation of suffering and created unconscionable indignity for both in the nursing home.



“...it’s not the first time I have been mistreated.”
-Mr. Williams

Lessons from Mr. Williams: Traditional Ethical Principles

- **Justice**—Hardships of poverty; inadequate access to care
- **Non-Maleficence**—Poor communication; perceived disrespect creates harm
- **Autonomy**—Inadequately understood; wishes not honored

Lessons from Mr. Williams: Toward Cultural and Social Understanding

There was a great divide between the life experience of Mr. Williams and his caregivers. His providers saw him as angry and difficult, which he was. Yet in their relationships with him, they failed to understand and empathize with WHY he presented himself that way. He was angry that his late diagnosis was related to being poor and uninsured. He resented that his doctors did not communicate with him effectively. He felt they misrepresented things, failed to listen attentively, and disregarded his suffering and needs. The result intensified his mistrust and suspicion. And ultimately, the decision to treat aggressively, despite the advanced stage of disease, led to shattered hope, more anger, and late hospice enrollment.



"I am grateful for the care I get here"
-Annie Dickens

Lessons from Ms. Annie: Traditional Ethical Principles

- **Justice**—Struggles of poverty
- **Benevolence**—Compassionate, interdisciplinary care leads to gratitude and spiritual support
- **Autonomy**—Respected as an individual

Lessons from Ms. Annie: Toward Social and Cultural Understanding

The story of Annie declares the dignity and grace of the human spirit in the midst of unimaginable suffering. It shows how social support heals throughout the illness experience. The narrative demonstrates the importance of spirituality and spiritual wellness in helping patients navigate the course of terminal illness. From her end-of-life experience, we learn that dying is far less about matters of the body than it is about matters of the person. We also discern that when the person is well-attended throughout the dying process--her emotional, social and spiritual needs being meaningfully fulfilled--that her suffering is greatly eased and she is deeply comforted.



“We were poor. Dirt poor.”
-Mr. JW Green

Lessons from JW: Traditional Ethical Principles

- **Justice**—Hardships of poverty; racism
- **Autonomy**—Paternalistic enrollment in protocol; non-informed consent
- **Non-Maleficence**—Inadequate nursing care results in bedsores
- **Benevolence**—Social support that “goes the distance”

Lessons from JW: Toward Social and Cultural Understanding

The vicissitudes of race and poverty shaped JW’s upbringing in the Deep South, as well as his adjustment to urban living as an adult. A lack of education, employment opportunity, and personal empowerment led him to a “life on the streets.” His adult character, tethered to the legacy of racism and poverty, led to a complex of irresponsible behaviors toward his wives and children. In turn, he was abandoned by them during his illness, and suffered the anxieties that surround loneliness in dying. A lack of education and empowerment resulted in misunderstandings of his disease and treatment, and compromised his ability to self-advocate with his caregivers. Stoic faith saw him through a life and death in poverty.



“He’s a doctor... When you go to a doctor you need help.”
- Mrs. Lucille Angel

Lessons from Mrs. Angel: Traditional Ethical Principles

- **Justice**—Hardships of poverty
- **Benevolence**—Support of family “goes the distance” and provides strong social and spiritual support
- **Non-Maleficence**—Poor communication about treatment protocol; spiritual abandonment by pastor

Lessons from Mrs. Angel: Toward Social and Cultural Understanding

Here we witness many of the human tensions that play out in illness. Mrs. Angel questioned why this was happening to her, becoming angry at God. She then felt ashamed at becoming angry toward the Holy One she loved and trusted so much. She shrieked in horror when her hair fell out, becoming disappointed in herself for such vanity. She was angry at the doctors who communicated poorly about her treatment and what to expect. She then sought to understand and forgive them, recognizing “they are only human.” Her body was cannibalized by disease. But her faith in God never wavered and neither did her daughters’ love and care giving.

Mindful Presence and Compassionate Understanding The Home-Visit Program

“Ya gotta go to where they live.”



“Oh, those eyes...”

I’ll never forget those sunken eyes.”

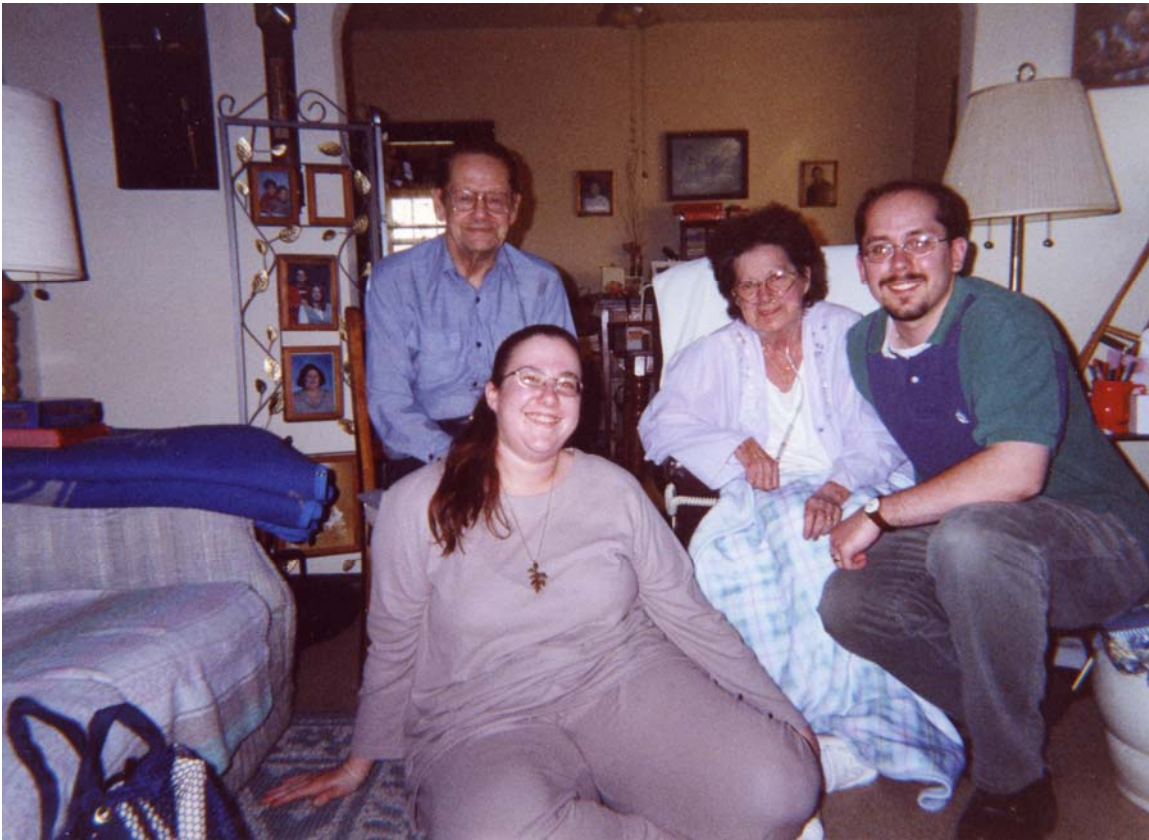
- 1st Year medical student

Patient-Centered Learning: Traditional Ethical Principles

- **Justice**—Understanding diverse populations
- **Benevolence**—Improved patient-centered understandings and skills related to empathic and compassionate care
- **Non-maleficence**—Deepened understanding of inadequacies in care and associated harm for patients and loved ones
- **Autonomy**—Develop person-centered understandings, including socioeconomic factors that hold sway over the illness experience; listening to choices/honoring wishes/setting goals

Patient-Centered Learning: Toward Social and Cultural Understanding

Most providers are relatively young and have little understanding of what it means to be seriously ill. Moreover, they typically come from very different social and economic backgrounds than the patients they will be called upon to serve in the inner city. For this reason, they often have less-than-optimal skill in communicating with patients and loved ones. By learning about the private and social world of patients, in the context of their homes and communities, the capacity of caregivers to relate to and care for their unique needs is improved.



“I worry about those students who haven’t had the opportunity to participate in this experience.”
-1st Year Medical Student

“Thank you for the work you do.”
-Milton, “the Cowboy,” Smith