

REFLECTIONS ON BIO-MEDICAL ETHICS: NOTES FROM THE CANCER WARD

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Diagnosed with acute promyelocytic leukemia after a regular blood test, I was urgently admitted to hospital on September 14th, 1999 where I was interned for five months. The treatment was aggressive: three hits of Adryamycine and Cytarabine, one week each, twenty-four hours a day geared to burn away all one's white blood cells, rendering the patient completely immune-suppressive, utterly vulnerable to the slightest bacteria. Recent budget cuts had already strained the medical and nursing staff, leaving residents under-supervised and inter-departmental relations dangling- a recipe for errors and abuse. What's more, the cuts gutted the institutions of any moral coherence. All that remained was the ethical stance of the individual professional, be they doctor, nurse or technician. Although attended by a compassionate, communicative and highly competent team of oncologists and haematologists, and cared for by responsive nurses, it was a roller-coaster ride through hell.

I had fevers of 42 degrees(centigrade), was pumped with antibiotics for weeks on end, had two bouts of blood poisoning and lay dying twice in Intensive Care, lost my gall bladder and hearing in my right ear, contracted renal failure, and developed lesions on my liver. I have seen people die beside me, learned that almost 10% of all oncology patients die of shock on the first day of chemotherapy, and found out that in many cases where chemotherapy is successful, other cancers are provoked. I've seen the sadness of those without hope, heard doctors lie to prevent despair, wished for more information myself and then prayed for none at all.

On September 16, I went into septic shock, bleeding into my gall bladder. Two Intensive Care Unit residents entered my room, highly animated, one whispering in the other's ear. They poked and probed and dug deeply into my stomach and intestinal area provoking sharp pains. They then announced that I needed to have my gall bladder removed, that I would not survive the procedure, and that they needed to know "within the next five minutes" whether I wished to remain on life support after the operation.

What I experienced forced me to question the basic assumptions of biomedical ethics: informed and presumed consent, patient autonomy and professional responsibility, treatment and therapy, quantity and quality of life, conflicting values of morality and law, as well as the myriad of cultural and religious approaches to death, suffering, pain and the status of the human species.

Does the doctor treat the disease or the person? Can he do both? If chemotherapy is the cure with all its attendant iatrogenic consequences, what is the disease? Cancer? Or death itself? Should the choice of treatment be the prerogative of the medical staff? Are the desperately ill competent to give informed consent? Has informed consent become a ticket to avoiding lawsuits and shirking medical responsibilities? Who determines whether further treatment is futile? Has the medicalization of suffering overlooked the importance for patients to find meaning and

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reorientation through their experience of illness and eventual death? Can communication be effective without a deep understanding of the patient's subjective world, their religious and cultural background, and their life experience? Without doctors having had either the same disease or a similar one? To what degree does the budget for healthcare impinge if not determine the range of ethical choices available, determining who will die, who will recover, whose pain will be prolonged?

Ours is a culture based on the fear of death; pragmatism reigns; medicine is here to prolong life. Any notion of a transcendent reality, or a genetic impulse to evolve through pain and illness has been stripped away. Where is the victory if medicine cures a disease, but robs patients of the opportunity to make peace with their lives, or renders them disabled through iatrogenic ailments? If we cannot come to see ourselves as part of a hundred-million-year chain of life and death, we will inevitably arrogate all decisions not only over other forms of life but our own kind as well.

Who can guide patients through their waking and sleeping nightmares provoked by the cancer diagnosis, induced by chemotherapy and sustained by debilitating side-effects? The triumph of modern medicine and clinical statistics is certainly a victory over superstition and early death. But while critical diseases are put into remission or even eliminated, the patient's heart and soul is often crushed.

My experience as a psychotherapist tells me that healing comes from being truly heard. What I do know from my own experience, as a patient is that the medical staff have little sense of what a patient subjectively feels, unless they've gone through something similar. Restricted to objective-clinical knowledge of disease, even a concerned physician's careful communication can be experienced by patients as brutalizing. The very aggressiveness of many treatments thwarts the patient's capacity to perceive reality. Ignorance of these facts exacerbates an already excruciating experience for the patient: one filled with shock, terror, dread, trembling, tears of rage and grief. Patients need time to absorb what's happening to them; for only in this fashion can they give themselves over to treatment. And sometimes there is no time. We are dumbstruck and speechless as our world shatters and the only reality we have is what lies immediately within and in front of us: There is the utter discombobulating shock of the diagnosis, the total loss of life as we knew it five minutes earlier, the utter dependence on hospital staff, multiple violations of IVs, shunts, needles, the shattering experience of septic-shock, the fear of going crazy with grief, the maddening and depersonalizing atmosphere of institutional life, the insensitive clinical evaluations of rounds, the invisible suffering of a body at war with itself and the paralyzing fear of the unknown. Without adequate psycho-social support in this, treatment, as effective as it is, simply feels barbaric. But the promise of modern medicine is often fulfilled. The patient's life is prolonged, but who or what is left? A semi-invalid, a permanent cancer-patient, or a vibrant human being eager to return to full time living?

The vast majority of patients trust their doctors, expect them to respect the Hippocratic oath and prolong their life without needless suffering. We cannot ask our doctors to be both

medical specialists and trained psychotherapists. Medicine has always been a bitter pill. Mutilation is implicit in the deal, but left unsaid for fear of scaring patients away. Errors abound. In a number of cases, the chemotherapy that cures will provoke another cancer later down the line. Often it gives more life, if not a new one. The profound question that cancer treatment asks each patient is the following: Is it enough to be alive? Which is more important to you: to have a happy life or to be happy to be alive?

It is September 16. I am in my room, distended in septic shock. Two ICU residents announce that I need my gall bladder removed immediately, that I will not survive the procedure and that they need to know "within the next five minutes" whether I wish to remain on life support. Terrified, shocked and scandalized by their approach I reach for the phone. I call a friend and request she contact a family physician and my brother, a diagnostic radiologist, 3,000 miles away. I hang up the phone and call the hospital operator requesting a rabbi. By coincidence one is in the hospital leading prayers among Jewish patients for the Day of Atonement. I am given last rights, the Viduh; I tremble and weep as I repeat the words: "If I do not find atonement in this life, may my death be an atonement for all the errors, iniquities and wilful sins that I have transgressed before you"... Out of the darkness a silver-haired face appears in front of me. He introduces himself as Dr. M, walks slowly around me, pulls up a sheet to cover my bare legs, draws down my gown and asks me to slightly lower my briefs. His hand hovers over my stomach and intestinal area. He grazes my skin with a finger, shakes his head and says: "There will be no operation tonight; the gall bladder is alive and functioning". All of a sudden it's dark again. I hear my attending physician speaking ever so slowly, carefully, and caringly: "If he opens his eyes, take his hand, for you'll never see him again". Then out of the blackness comes a face: blond hair, blue eyes: "Hello, I'm Dr. S, Chief Resident in ICU; I'll be your doctor tonight". I feel suspended, caught in flight, held by her gaze, her face floating above the bed, my eyes seemingly wide open. I spend the night in ICU, fighting for my life, filled and pumped empty until my blood-pressure rises, and the infection abates.

Morning brings the realization that I am alive; tubes, shunts and monitors surround me in a glassed - room. Three days later I return to the oncology floor. Somewhat dazed I get up and wobble down to Intensive Care looking for the blond haired and blue-eyed face. I spot one of the residents, asking where I could find the Chief Resident. "Something happened that night", he remarks as I wander down the corridors. I spot someone from afar and approach. "Are you Dr. S?" I ask increasingly overcome with tears. "What's the matter she asks?" "Nothing, I just wanted to thank you for saving my life the other night". Nodding "No", she says, "I didn't save your life, "God did: but he did it through me".

I believe it was the dignity bestowed upon me that was the critical factor in my survival that night. "Do no harm" is the basis of the Hippocratic oath. In those words lie a profound respect for the sick and a reminder of humility for the healer. Can modern medicine maintain a sense of the sacred? Can we see the person behind the symptoms and the disease?

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BLESSED ARE THOSE

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It is spring today, March 21, 2000. It's been five months of chemotherapy, septic shock, diarrhoea, liver lesions, kidney failure, hearing loss, intensive care, neutropenia and finally renewal. I write this as I await the final chapter: the rising neutrophil count that will signal a functioning bone marrow and cure from acute promyelocytic leukemia. It's been a hard road to travel. It's the quality of the nursing care that made it bearable.

The nurses take our vitals, change our dressings, give us injections, and hang our antibiotics and chemotherapy. They fetch us food, microwave boluses for makeshift hot water bottles, massage our limbs, bathe us when we're weak and assuage our distress.

But this floor, 7 Medical, is unlike any other in the hospital. This is not palliative care where all are resigned to the patient passing on, nor transplant where hope springs eternal, nor surgery where repair seems guaranteed, nor birthing where joy reigns supreme. This is a floor like no other; we are patients unlike any other; to choose to be a nurse here is a choice unlike all others.

We are the needy, frightened, confronting life-threatening illnesses. We emote spontaneously; we weep and wail, act out and expect our nurses to read our minds. We are often irrational, demanding and downright paranoid in the days and nights when the demons come out. We regress and strike out at those in front of us, and who is most often there if not our nurses. If we are not important to those who tend to us, who then?

Here we live and die, we fight like heck for our lives and part of our fight is drawing the nurses close to us because without that intimacy we couldn't make it. Some die and when we die, they grieve: for those of us who do die it's all we have: the knowledge that we were important to

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another human being. And this is the burden of nursing on this floor: being constantly aware that each life is a fragile one and a finite one, to know that modern medicine to which they are dedicated can work, but not for all, that miracles can happen but crisis can erupt without warning and death strike. Our nurses carry within them all the faces of their patients and I wonder how they deal with this constant attachment and loss: and it is loss whether the patient is cured and walks away or dies under treatment. How do they live normal lives at home? What strength do they have to bring children into this world? How do they provide care without being sucked into our anxiety? One either embraces life fully or goes mad it seems to me. Anyone who can't, finds no place in oncology.

The eyes they look into are fearful, searching for solace, often dumbstruck with terror. Alone in our beds, lonely in our souls we depend on the nurses for emotional succour, for understanding, if only to assuage our guilt for the tiff with our spouse, or wash away the quick word we just had with a visiting child. As each ache, pain, burning sensation arises we cry out, moan, bitch question our nurses frantically whether this means impending crisis or merely par for the course. At moments like this a wayward word devastates us; the appropriate one gives us courage to go on.

At nights and on weekends, they are our lifelines. We hope and pray they have the right answers because the doctors are few and far between. Now our dependence is flagrant, our demands insistent.

When the room next door is being emptied we know what we don't want to know, that one of us has gone and no host of angels or medical engineers will ever bring them back. And we tremble and weep deep inside.

How do we navigate in this crazy oncological world where "acute promyelitic leukaemia is the best one to get", where "diarrhoea is proof positive that chemotherapy is working"? How do they? How do our nurses retain their balance, neither drown in our sorrow nor turn cold to our plight, nor sacrifice their families to their profession?

Blessed are the nurses who make us whole again, day and night; the nurses who come with a smile and a laugh, the nurses who read the fears behind our brave fronts, the nurses who hold our hands through the bone marrow biopsies.

Blessed are the nurses who run downstairs to get our platelets and blood or across the hospital grounds to deliver a culture, the nurses who answer our calls even if they weren't assigned, those who take time with an injection and place the thermometer gently in our mouths.

Blessed are the nurses who credit us with intelligence, who call their colleagues to attention, and those who tell us the gritty truth when we need it.

Blessed are the nurses who dropped in just to say hello, who turned a blind eye as I snuck a fridge into my room, the nurses who danced salsa and meringue with me in the wee hours of the night, and those who asked the same repetitive questions at every watch, for it made me feel secure.

Blessed are those who allay our fears, give us hope and nurse us through this nightmare.

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