Personal Narrative

The ethics of offering a dignified death

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I was an Army brat in the days when the Indian Army was a rather small outfit. That is how I met CG. Both our fathers were from the Artillery, so inevitably, we ran into each other several times over the years. Most of our early interactions were short-spaced since postings change every two to three years in the army. It was in Poona, however, that we interacted unabated for four years and became friends. We were in the same school, even though she was a year older and in a senior class. Our journey in life after school unfolded differently. In spite of this, we remained in touch with each other. Our parents were friends, and so were we. There was a comfort in the similarity of our backgrounds, and we never had to explain ourselves.

This is CG's story, and I am telling it because she cannot.

CG called one evening in March 2019 and said she needed help. She had discovered a lump in her breast and wanted to know how to proceed. She was a widow who lived alone, and I toyed with the idea of jumping into my car, but it would take me over an hour to get to her house, provided the traffic was light. I suggested, instead of me driving over in the twilight, that she make an appointment with a surgeon for noon the next day. I would get to her home at 10 am to examine her and then accompany her to the doctor.

I discovered a firm, biggish lump in the upper outer part of one breast and a smaller lump in the armpit on the same side. Having been a pathologist for fifty-odd years, I knew that, clinically, the probability of it being malignant was high. I had performed fine needle aspiration as a diagnostic tool in countless breast lesions in women – and men – in our hospital, and I could easily visualize the kind of cells growing in CG's body. I tried to sound optimistic when I spoke to her, but I also avoided misleading her with fake reassurance.

We met the surgeon at noon. He examined CG and made notes, listing the required investigations. He said he'd be away to a conference over the next three days, but on his return, he would reassess her, review the investigation reports, and then perform a biopsy. I asked him to consider a needle biopsy now so that the report would be available when he returned and he could take a call on the type of surgery much sooner. He agreed!

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Four days after noticing the lump, the diagnosis of cancer was established. Subsequently, she underwent a radical mastectomy on one side. It was a Stage II carcinoma breast. Following the surgery, she was put on prolonged hormone therapy as her tumour was positive for hormone markers. Since it was negative for other markers, no other drug was given by the medical oncologist. She was advised to have regular follow-ups every three months. She did well on this regimen and even travelled to visit her son abroad.

Almost exactly one year later, in March 2020, the COVID pandemic started in earnest in Delhi and in the National Capital Region. This threw a spanner in her follow-up regimen. Hospitals were teeming with people who had COVID, and the fear of catching the infection loomed, so she stopped going for follow-ups. Anyway, she was doing well and currently required no further treatment.

The following year, in May of 2021, she broke the upper end of a femur. Histopathology revealed a metastatic adenocarcinoma at the fracture site. PET CT showed metastasis to the brain, adrenal and bone. It was now stage IV disease. Circumstances had not been kind to her.

In addition to the hormone therapy she was on, many chemotherapeutic drugs were started. She did well to begin with and suffered only a few of the usual side effects of the medication. This went on for about a year. When resistance developed to one drug, another was started. When CT findings showed disease progression, the treatment was changed. Thus, it was the CT-scan that dictated change in management. Clinically, her symptom-free period reduced considerably. She additionally developed fever, diarrhoea and convulsions. The disease continued to progress, and she developed liver and renal metastasis.

Till her passing in February 2024, she continued with one form of chemotherapy or another. She weakened slowly over time until she was unable to sit or stand unaided. She was disoriented at times and was getting sicker by the day. She needed repeated admission to the hospital for blood transfusions or for infections.

I discussed palliative care with her three months before her death. She shot it down claiming that none of her doctors had taken up this subject with her. On every visit to her oncologist, she had been reassured that there were many drugs in the arsenal of chemotherapy available to her. There was always the promise of yet another new drug that would surely work. Thus, she continued on chemotherapy even as radiology showed disease progression, and there was no question in my mind that she now had chemotherapy-resistant cancer.

It troubled me greatly that she was not offered palliative care. It continues to bother me. Are doctors not duty-bound to discuss the forms of treatment in the light of prognosis with their patients? Is a good oncologist one who fights to the bitter end, never mind the prognosis or the toxicity and the resultant discomfort to the patient, or is it one who recognizes that treatment is now no longer effective and seeks to make the patient comfortable in their remaining days rather than to prolong a life of suffering? How ethical was the way my friend was managed towards the end of her life?

Another friend of mine had a different experience with her terminal illness that I believe had a lot to do with the patient and her family choosing to include palliation experts in the care.

LS is a ninety-year-old friend with dementia. She developed difficulty in breathing and radiology revealed lung lesions along with fluid around her lungs, and a mass in the pelvic region. Fluid cytology showed an adenocarcinoma. She had metastatic stage IV disease with an unknown primary tumor. Her two daughters and their husbands were her support group. In concurrence with the oncologist, it was decided to give her a trial of chemotherapy with a ‘mild drug’. However, she became even more disoriented after the first dose and additionally developed nausea, vomiting and loss of appetite. It was, therefore, decided to stop chemotherapy and put her on palliative care. Five months into the diagnosis she is comfortable with no pain. Her scans shows disease progression, but her quality of life is decent, and when any symptoms appear, they are immediately attended to, which is a major cause of relief to her and to her family.

In CG’s case, when all forms of treatment failed to curtail the disease and the disease spread unchecked, was it not an indication that the cancer was resistant to treatment? When treatment causes as much harm to the patient as the disease does, when toxicity outweighs any benefit, whose job is it to mitigate suffering? Should I have pressed harder? Would my insistence have been viewed by CG as interference? I was, after all, a friend – albeit a clinical pathologist myself - and not her oncologist. She had great faith in her treating doctors even when I found their reluctance to address palliation a deal-breaker.

Quality of life is paramount for the patient and their family, who face challenges associated with a life-threatening disease. When all drugs targeting the cancer are ineffective, the patient must get supportive care to keep them symptom-free and to maintain their nutritional needs. Palliative care touches on all aspects of a person’s life and illness. Problems are anticipated and prevented or are dealt with immediately as they appear. As a result, the patient feels better cared for, and the caregiver gets the appropriate guidance. I know because I’ve been there and have witnessed first-hand how quality of life and mood, and even long-term survival, are improved if palliative care is started early.[1]

Clinically CG’s symptom-free period slowly but steadily decreased, and she went from the breakdown of one organ system to another – and from one toxic side effect of a drug to another. A stage came when chemotherapy was harming my friend more than the malignancy. Palliative care should have been discussed with her as well as with the family. Could I have advocated better? I don’t know if I would have been heard. CG had a misplaced belief that things would turn around for her. She may have equated palliative care with giving up. I wonder if her oncologists also thought along those lines?

To me palliation means solace, support, and mitigation. It means comfort – for the patient and for the caregivers. It should start almost as soon as a life-limiting diagnosis is made, should be in tandem with the medical and surgical treatment, and should continue after targeted treatment becomes pointless. At the end of life, palliative care is the ethical way to do things.

Reference:

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