

## CARING FOR WHAT MATTERS

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“**S**he has a temperature of 40. This was the last straw. I wasn't very keen on trying a fourth chemotherapy line... You go tell them.” he told me abruptly. “If they want to talk to me, I'll be here tomorrow. I started her on Tazo. Level of care 3.” The oncologist left.

I took the patient's chart. Room 1724. It was an East Asian name; someone from India or Bangladesh, I guessed. I flicked through the pages quickly, my hands quivering. Breaking devastating news to a patient I was meeting for the first time... How? I came across a terse summary sheet of a previous hospitalization. Thirty-three years old. Rhabdomyosarcoma. Amputation of the right arm. Intradural spinal mets; paralyzed bilaterally in the lower extremities. I closed the chart.

“What are the patient's vitals?” I asked the nurse.

“Temperature is 104.2. Tachy at 144. Hypotensive at 96/45.” she replied.

I took a deep breath, knocked on the bedroom door and walked in. She was lying on her bed in a hospital gown wearing a beautiful scarf that contrasted with a dull complexion and dark circles under her eyes. An empty gaze. At her bedside was a man. A pink backpack with colourful cartoon imprints was hanging near his feet – probably their child's. He held his head in his hands while gently stroking his temples. What was I supposed to say to this woman at the end of her life? I froze. It was just my second month of clerkship and I was without a single idea what to do.

“Is there anything I can do to help?” I asked.

“Her back hurts.” the man replied.

“My mom is in Pakistan. I want to see her.” she stated.

I took a brief history. I questioned her as much as I could and deemed appropriate but felt daunted by the acuteness of her febrile neutropenia compounded by the tragedy unfolding before my eyes. At loss regarding what to do, I paged the Palliative Care team for help. The Palliative Care staff said we could meet in the ER.

"So, what's the story?"

"Febrile neutropenia after last attempt of chemotherapy. Thirty-three-year-old female. Metastatic rhabdomyosarcoma. Bilateral lower extremities paralysis. Vitals are improving on Tazo. She is in profound pain."

"Does she have family? What is her cultural background? How has she been dealing with her disease since the diagnosis?"

I did not know; this empty answer triggered a sense of shame in me.

"You know the disease, but not the patient. Come with me."

It was my first exposure to Palliative Care. I had read about it but putting faces on this approach altered the experience. I feared telling the family I had consulted the Palliative Care team. What was I afraid of? Did I see it as a failure of the medical team to treat her disease? Yes, in part. Was I afraid to say the word "death"? Yes, indeed. I was confronted, for the first time, to my own existential fear of death.

I approached the patient with my preceptor and discovered a totally different person than the one I had met earlier. During this encounter, I learnt that Daniyah\* and her husband immigrated when she was 28. In her own words, getting a Canadian visa was the best thing that had ever happened to them, along with the birth of Raka, their 4-year-old daughter. She was diagnosed at the age of 30. For Daniyah, illness affects those who are strong enough to bear it. This is what she told me during one of our daily encounters later that week. She has always been strong: for example, she was a pro-democracy activist in Pakistan. Since beginning her treatments, Daniyah has suffered from severe back pain. She was informed that it would ultimately get better one day – but she was still waiting for that day to come.

This first experience in Palliative Care made me realize that the discipline is not about "accepting death" rather, it's about enabling people with life-threatening illnesses to live with an optimal quality of life. This perspective should be kept in mind in all areas of medicine. With chronic disease management being central to the practice of modern medicine, quality of life should be discussed more and never taken for granted. Medicine is not only a science of averting death and prolonging life. In fact, Palliative Care is one of the few fields in medicine where life and death are regarded as normal processes.

Physicians deal daily with patients' lives, births and deaths. As a medical student, I think we should be able to discuss it in the same way we counsel patients on other matters related to their health status and well-

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\*Note that names and other patient's identifiers used in this essay were changed for privacy considerations of the patient involved.

being. Palliative Care demands a holistic approach that deals with the physical, psychological, social, and spiritual suffering of patients and their loved ones. It is one of the areas of medicine where I felt that we do not treat the patient according to what conventions require, but based on what the patient wants, feels and believes. Treatments are impressively patient-centred and my rather short, but meaningful, experience taught me that this should be the favoured approach in every field of medicine.

Why was Daniyah suffering since her diagnosis? In my opinion, Palliative Care should not be a “last resource.” It should be applied early on in the course of an illness where distressing symptoms are difficult to manage, in conjunction with other therapies intended to prolong life. By enhancing the quality of life of patients and their relatives, Palliative Care may even influence the course of diseases [1, 2].

A few weeks later, I saw Daniyah in the cafeteria accompanied by an older woman pushing her wheelchair. She was about to be transferred to a hospice near her home, where her husband and daughter could visit daily. With the help of a social worker, her mother managed to obtain a visa to visit her. They looked strikingly alike. Daniyah was doing physiotherapy daily; it was making her feel “better and stronger,” she told me. Her family was meeting with a spiritual counselor to help them find answers to their questions but also to embrace the unknown. Her gaze was new to me: this time, it was peaceful and serene.

Three months have passed. Daniyah has been in my thoughts ever since I first met her. I never learned what happened to her after her transfer to the hospice. Meeting Daniyah was truly enlightening; it changed my perspective, not only on the role of Palliative Care in medicine, but also on medicine as a science of caring, healing, and relieving suffering [3].■

## REFERENCES

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