

Be a true listener, rather than a good conversationalist

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Abstract

Oncology patient care is an ever evolving field both as a science and a clinical art. We evaluate, diagnose, and treat cancer patients daily. We break the bad and the good news to them. We are the hope on which their life and dreams hang on. We, as practitioners, have to assess each patient as an intelligent observer. We have to devise our strategy to break heartbreaking news to them in a tailored and personalized fashion according to the physical, psychological, emotional, and social status of the patient. The process has to be gentle, perceptive, pragmatic, yet truthful. These need to be reasonably good observational, listening, comprehending, and delivering potentials; which are sharpened by experience and skills.

Key words: End of life, palliative care, Royal hospital

“Deep listening is miraculous for both listener and speaker. When someone receives us with open-hearted, non-judging, intensely interested listening, our spirits expand.”

- Sue Patton Thoele

I always remember the words of my pediatric medicine professor in Karachi, Pakistan, when I was an undergraduate medical student. We often used to ask him to recommend a good book to read and consult. He used to reply very philosophically, “Your patients are your books, go and read them.” We then were never aware of the depth of his notion. While looking back on this stage of my profession, I feel proud and do not doubt that I learnt a lot from my patients, may be more than anything else. This practical real time learning is certainly not less and is possibly more as compared to the learning from all the books that I ever consulted. Medicine is quite unique in the aspect that one’s learning involves breathing and pulsating living beings rather than books or machines or computers. We must dedicate our successes and achievements to those human beings, who often may have lost their struggle of life to this disease, but taught us the lessons of our life time for the times to come and to be used for improving our understanding and approach to this fatal disease and its outcome.

I can’t ever forget that cold winter Wednesday afternoon at Royal Surrey County Hospital Guildford UK, in 1988. It was depressing for most of us who moved there from the sunny long hot days of East Asia as the sun used to

set early and it used to be freezing cold outside. I was finishing a busy day’s work and taking a quick last look at patients along with my junior before going home. In those days, duty hours were longer and rest was something you always eagerly awaited. I reached this middle aged male patient Mr. JPW. He looked at me and stated, “I hope my reports have come.” I glanced at my senior house officer, who nodded his head in the affirmative. Mr. JPW was a single, never married British school teacher in his fifties, with no family or relatives. I never saw anyone coming to see him or enquiring about him. He was admitted with a provisional diagnosis of acute myeloid leukemia in blast crisis. He looked a bit depressed and enquired about his blood film and bone marrow examination reports. I knew all this background and wanted to sit with him for some time when breaking this unfortunate news to him. I thought for a second to postpone this discussion until tomorrow, when I would have more time and would be fresh enough to give him the time he needed, which would satisfy him. He however came out with a heart breaking comment, “I can understand what the reports might be.” This sentence struck my heart like a bullet and moved me very much. I told my registrar to go ahead with his commitments and I pulled up a chair and sat beside him despite all my tiredness.

I sat with him that afternoon for almost 4 hours. He spoke for 220 minutes of these 4 hours while I hardly spoke for 20 minutes during this time, just giving nods and signs of understanding. However, I was all ears and listened intently. He talked on almost every topic from his disease and personal life to football and politics. I realized how lonely he was. He was a bit tired by then needing some rest. I observed that he was comfortable, satisfied, pleased and thankful. I said good bye to him, assuring him that I would see him again in the morning. Next morning when I reached hospital, I was shocked to discover from the on-call doctor that Mr. JPW passed away peacefully in the early hours of the morning just the week before Christmas.

The doctor on call gave me an envelope addressed to me by Mr. JPW. I opened the envelope with wet eyes. There were surprises in it. There was a short note for me, which

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I still have after all these years. It said in very simple words, "Dear Doc, I struggled year after year, but life was not easy or simple. You sat with me for only a few hours and made my death so easy, comfortable and acceptable." He gave me a responsibility as well to perform on his behalf. There were three cashiers' cheques in that envelope, which represented his entire life-savings. He requested that one be given to an NGO working for a children's charity and the other one for a leukemia support group. The third one was to a nephrology unit to buy a dialysis machine. I remembered that his late sister was on dialysis before she died. I did all of this as he asked, to the best of my ability and felt proud that he had entrusted me with this responsibility.

My eyes still become wet on December 20, every year always remembering him. I can never forget Mr. JPW, for many reasons. He taught me something very basic, integral and very essential in my early career as a doctor and oncologist. Every management, with either palliative or curative intent, always begins from being a good listener. It may well start being a good listener and finish just there, being often the only modality required in the oncology practice of the terminally ill. We clinicians don't realize and always underestimate the value of listening to a patient being all ears.^[1] Second was his intention of doing something before he left, giving a consideration of charity. Thirdly, the patience and acceptance of what was the reality and that it was all over for him. Last, but not the least his attitude of gratitude and thankfulness. May God grant him peace.

The lessons, I took away from him are always indirectly shared with almost every resident and trainee I teach. I am enormously grateful to my patients for teaching me what is important in life for family, community and future. It is my utmost duty to transfer this experience onwards. I am, as an oncologist, assailed by the feelings of sadness, trepidation and gratitude. It is overwhelming to think and remember hundreds of those sweet patients, who were diagnosed and bravely walked through treatment until death. No thanksgiving is profound enough to reciprocate the gifts of wisdom, bravery, humor, optimism and friendship that I have received from them.

Many patients often don't remember the details of their disease, but they always recall how their diagnosis was disclosed to them.^[2-4] Majority of patients want to know the truth (Parker)^[1,5-6] There are legal and ethical considerations. A physician's competence in these scenarios is critical to establish trust.^[7-8] Both, patient and physician should be comfortable and the requested members of the patient's family should be present. An experienced physician will always establish at the start how much the patient

knows and how much he is keen to know. A key to the conversation is to share the relevant information and respond to the patient's feelings. It is required to synthesize the patient's concerns and outline a stepwise manageable and accepted plan.^[2,4] SPIKES is one such stepwise strategy plan, which can be adopted in breaking the bad news.^[9,10]

Everyone has to die and having a terminal illness makes death happen sooner. Most patients expect the experts to serve as anchors.^[2,4] A patient will often say or do something that lets you refocus on the truly important things in life. Many health-care givers are fearful of death and feel uncomfortable being around a dying patient.^[2-3] This is further increased by burnout and feeling of a failure. Their trepidation compromises their ability to care for dying patients. It often doesn't matter who is listening, a junior resident or consultant. It is independent of specialty or level of training. End of life-care is a real balance between science and art.^[2,7,9] The grave end of life conversation needs sensitivity and light touch. The experts must learn and excel in empathy, which is associated with fewer medical errors, more patient satisfaction and a better outcome.^[7] End of life and death can be made comfortable, respectful and dignified, which everyone deserves. We have to be advocates for a smooth transition from cure to comfort, whenever appropriate.

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