Coming back home from a long shift one day, at the front door I was confronted by several neighbors surrounding my mother who was lying on the floor. She had a broken leg and was moaning of pain. “You will be fine, Mom!” I repeated several times, though I knew it was not going to be an easy ride.

She was in her 70s, a relatively healthy woman who managed all the house chores by herself. A retired university librarian, she always had a few humorous stories to tell about her interactions with college students to cheer me up when I came back from long night shifts during my medical internship.

She rarely complained of anything until one evening when what seemed to be a minor backache was bothering her. “Did you carry something heavy again, Mom?” I asked. “It was only a small shopping bag,” she answered with a guilty smile. Through the next three weeks, her backache turned into radicular pain. An evaluation by a neurologist, who was a former classmate, comforted us that the pain should be stemming from a minor discopathy and prescribed ibuprofen, a muscle relaxant, and adequate rest. However, the pain did not go away.

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She was transferred by the ambulance to the hospital where I was working and a thorough evaluation revealed that her backache, the nasty radicular pain, and the broken leg were due to a spinal cord compression syndrome. She underwent an operation and the pathology report revealed breast cancer—very odd presentation for a common type of cancer.

As my mother was undergoing diagnostic assessments and procedures, I spent my evenings reading about how to give bad news to her. The 6 steps of SPIKES protocol for delivering bad news are (1) setting up the interview, (2) reviewing the patient's perception of the illness, (3) getting an invitation from the patient to deliver the news, (4) giving the patient knowledge and information, (5) responding to the patient's emotions, and (6) summarizing the treatment plan and reviewing all that has been communicated. I wondered if the authors of the SPIKES protocol had performed it for a close relative. It would be very difficult providing information with honesty without destroying the patient's hope.

It felt like a relief that my mother would never ask me any question about her disease. “…YOU are my doctor and YOU know what is best for me.” So, during her cancer treatment, I was the one who signed the informed consent form, undertaking all responsibilities and decisions.

It is a common practice in Iran for the physician to withhold stress-inducing diagnostic and prognostic information from the patient undergoing treatment. The physician is seen as a higher authority who will decide on what needs to be communicated and what does not. What about the patient's autonomy? Did this so-called paternalistic approach to medical care overruled my mother’s real wishes at that time?

Was she aware of her terminal diagnosis? One day I overheard her conversation with a friend: “I have that BAD disease, and I know this is my last journey.” In avoiding a direct and frank conversation with my mother about her illness, I wonder whose emotions I was protecting, hers or mine? Actually, I was not feeling prepared to manage her emotional reactions and feared to lose her trust in my abilities in the face of an uncontrollable disease.

Years later, I wonder how the end-of-life experience might have been different if I had been upfront with my mother about her diagnosis. Would that have empowered us to share our emotional journey together, make more individualized care decisions for her and reflect on life we had together? Would that have prevented the last chemotherapy she received...
a week before dying?

The cancer experience deeply affects the whole family. It is common practice in Iran, and is promoted by the medical community, to withhold information from the patient and therefore not include the patient's wishes in care planning. Although this approach is intended to protect the patient and the families from emotional suffering, it has its consequences. Supporting and enabling the family is universally one of the palliative care objectives. According to the World Health Organization, “palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness through early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual.”

In the common medical practice in Iran, the cancer care provider is set to limit information sharing with patients and sometimes families when it comes to poor prognosis. Involving the patients, as well as the family members, in their care journey and enabling them to gain control of their life decisions is important and an inherent shirt the medical community needs to take into consideration. This is especially timely, with the emerging shift in care paradigm from physician-centered care toward patient- and family-centered care. The family, as the physician's partner in the process of care delivery, needs to be taught, supported, and receive care, especially mentally and emotionally. Their concerns should be understood, and their questions should be answered as the family is one of the cancer care pillars.

References
5. WHO Definition of Palliative Care [Available from: http://www.who.int/cancer/palliative/definition/en/]

Delivering bad news