Learn From Others, but Don't Forget to Think on Your Own

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Back in the 1970s, collaboration was far different and far more difficult than today. There was no Internet then and no phone conferences via Skype, but along with representatives from Europe, we organized the Coordinating Committee for Human Tumour Investigation [1]. Counted among its committees were the tissue culture group based in London, U.K. (directed by Jack Ambrose), and the laboratory of Georges Barski (Villejuif, France) where the first in vitro cell hybridization was done [2]. I had the tremendous opportunity to visit with Barski, which also allowed the opportunity to accompany Georges Mathé, the famous pioneer of bone marrow transplantation [3], on clinical rounds. Even years later, that is a day I will never forget.

Rounds with Mathé focused not only on clinical evaluation: he made it a practice to seek our opinions of how to treat the patients. We, in turn, would cite the literature, hoping to show that we had a good grasp of the worldwide publications, of the evidence that supported our recommendations. Yet, as one person proceeded to give an “evidence-based” rationale for his opinion, Prof. Mathé proclaimed:

“It is well that you are aware of the recent publications, as it is necessary to learn about the experiences of others, but the published data will not always hold the best advice for what to do in research or how to talk to your patients. Sometimes patients will need alternative approaches.”

I will never forget this message. Mathé did not wish to discount the published experiences of our peers—indeed, ignorance of the published literature should not be encouraged—but to help patients, looking beyond the literature is sometimes necessary. Although guidelines and

quality standards may be in place, the management of our patients must focus on their particular circumstances, or who they are as individuals. This is especially true when it concerns communication in the context of palliative cancer care. This

situation is difficult because prognosis is very hard to predict, and even the most experienced clinicians will find it difficult to “translate” the facts while being aware of and showing respect for the patient’s individual feelings [4].

Such a situation occurred in 1994 in Pesaro, Italy—the city of Rossini and Pavarotti—where I was visiting patients within our home-care project of ANT Italia. I stayed in a hotel that was close to the sea and that was owned by a generous man prone to helping people without regard to his own needs. Sadly, I was there because the owner was the one in need of aid from our service. His son (only 35 years old) was ill, and nobody could tell him from what. The family suffered from the unknown: open questions unanswered and doubts not easily expressed.

“Thank you so much for coming,” he said. “We have great problems with my son.”

“Please,” I replied, “show me everything you have from your doctors . . . letters, x-rays, computed tomography.”

“There is a lot, yet the doctors have no diagnosis,” he continued. “All they have done is refer to a different doctor.”

He supplied all the records he had, and I went to my room to review them. It did not take me long to identify the diagnosis: advanced renal cancer with metastases in the bones and the brain. I was shocked that no one had told the son, or the family, the diagnosis or that the patient was going to die. I kept imagining a father without a successor for his hotel and the loss

Cover image of the author's book, *It Will Be a Wonderful Spring*.

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of a son and a very close friend. At that point, they had no idea what was coming.

I had arranged to meet the hotel's owner the next morning and had hoped he would come alone; however, both father and son greeted me. I could sense their optimism that the professor from Germany had an answer!

For a moment, I struggled with what to do. Should I hide the truth, play it down, send them to another specialist? After all, come the evening, I would have left this hotel. Should I ask to speak with the father alone?

Ultimately, I did not say "cancer" or "chemotherapy" or mention that the son would die of this. Instead, I exclaimed, "I will tell you what is to do! The situation is complicated. The patient must go urgently in the hospital in Monza. I know the doctors. . . . Without doubt, your son cannot work as usual in the next month."

The son accepted my advice, without questions and without any protest. He was full of hope, already calculating the time until his return to his job; however, the father took this news differently. Looking tired, he exclaimed, "This is all very hard for us! However, as you see, my son, as always, will fight. I am grateful, though, that ANT wants him to go and offers hospital-at-home care after the stay in Monza. . . . I want my son to always be here." Although his words did not mention the sad fate awaiting his son, his face showed me that he understood the situation.

Although so much time has passed, I have never forgotten this experience. One could question whether I handled it appropriately, but I think I did. You see, I believe patients have a right to the truth—the best data, diagnosis, and conversation about prognosis—but patients also have the right to the "nontruth," especially if the truth may destroy hope.

Ultimately, the evidence basis of medicine can take one only so far, particularly for our patients with advanced cancer, and can provide little guidance on how to communicate what we need to tell patients and what patients want to hear. One must embrace the tenets of medicine, the best evidence, and the guidelines; however, one must never lose sight of the patient. Sometimes the help they desire is the kind not found in textbooks [5, 6].

Another more personal example illustrates this even further. One of my coworkers had cancer and had reached the end of life. She knew how emotionally hard it was for me when I was with my own patients who were terminal, the sense of helplessness and sorrow I felt. Yet, even as she reached that point, she still tried to help me.

I was sitting close to her bed, and as usual I was very unsure of what to say, what to do. What could I tell her without taking away any hope she might have had left? As I sat, it seemed that my rationality left me, and I was left with the unbelievable grief that I was going to lose this wonderful person. Overwhelmed with sorrow, I was not able to adequately talk to her. With one phrase, she put me at ease. I still remember, she looked in my eyes, took my hand, and said, "It will be a wonderful spring this year." Her eyes told me, "I know it will not be my spring." I pressed her hands, and a few days later she died in peace [7].

I understand now that there is no easy way to discuss the end of life, as a doctor or as a patient; however, communication is a two-way street, and this should never be forgotten. Although clinicians may be most concerned about how to help patients, these experiences illustrate how our patients sometimes help us.

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