The art of medicine

Critical conversations: navigating between hope and truth

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"I am afraid the chemotherapy is not helping."

"Please don't say that", she sobs. "I feel I have no hope."

My fight or flight response kicks in. Suddenly, I hate this conversation that moments ago seemed so important. I am ready to do anything to avoid being branded as the destroyer of hope. Why should I take on the burden of contaminating our easy relationship?

But I have lost count of her drugs. Every treatment is toxic. The central line hurts. She has lost her hair, endured multiple infections, and suffered nearly continuous nausea, vomiting, and fatigue. She has spent more time in the chemotherapy chair than with her youngest child and is prone to the most disabling side-effects. After several nights of steroid-induced insomnia, she said "My mind is racing, I want to kill myself." The fluid loads bloat her. When her skin peels she cannot walk. Her cancer returned barely a year after supposedly curative surgery. Various therapies kept it under control but lately there have been signs of resistance. She was so distressed recently that I sent her on a round of second opinions. It took nearly 2 months of expensive tests and appointments to conclude what we all knew: there was no cure.

While away on maternity leave, I half-expected her to succumb to the disease. On my return, I see her deterioration at first glance. Where she smiled in greeting, she now winces. Her continuous pain is untouched by a cocktail of drugs. Perhaps I had lost sight of the intense toxicities, but having been away has given me fresh insight into her troubles. I discuss ameliorating her entrenched symptoms, realising that she herself expects little respite. "A whole day feeling good, what would that be like?" she says dreamily. But when she continues to regard chemotherapy as a necessary evil, it strikes me that in all these years, it is almost certain that no one has ever suggested otherwise. After all, she is not yet 40 years old and the mother of three young children. Of all the patients we sell hope to, she would be the first.

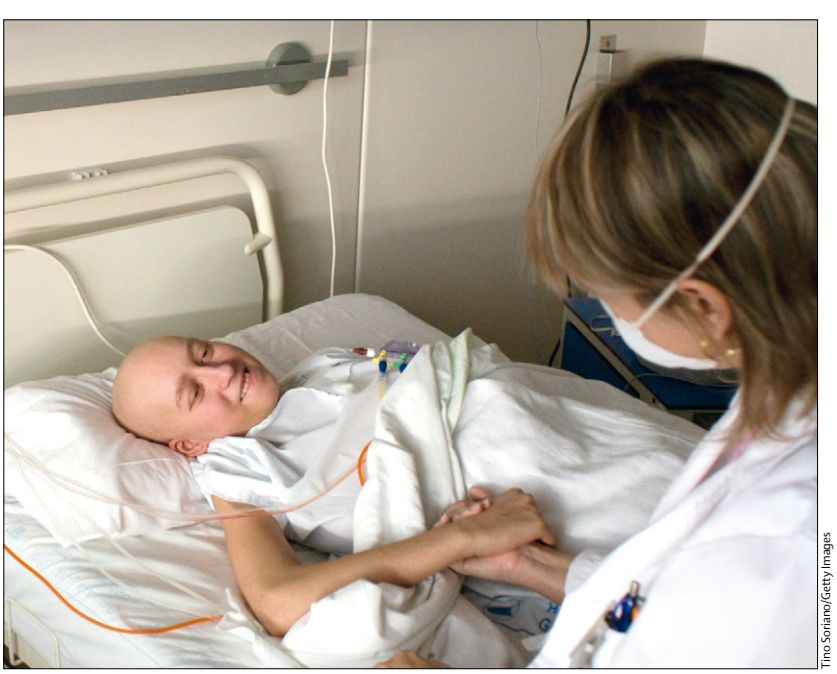
I leaf through her notes. Every piece of correspondence since her early recurrence has forecast a gloomy outlook, but then someone is tempted by a new beacon of hope, however faint: a new clinical trial; a new specialist; a trial drug on compassionate access. She has seen every expert in the field—oncologists, surgeons, and radiologists. Incredibly, nobody has thought to tell her that every one of these costly, time-consuming, and often painful interventions has a diminishing chance of benefit and a rising risk of harm. Everyone expected someone else to have the difficult conversations.

Confronted by the seriousness of her symptoms, I feel obliged to discuss therapeutic harm. "Tell me what you want to achieve." She looks at me as if I am mad. I persist. "People often talk about goals in life. What are yours?" Her husband's answer is deadpan. "To be cured." She covets life, in both quantity and quality. I can only do something about the latter. "I think the chemotherapy is making you sicker. You should consider stopping."

About to speak, she instead begins to scratch her arm vigorously. "Oh, we forgot to tell you she has developed a bad itch", says her husband. Just then the nurse knocks on the door. I turn my attention to her liver function tests, screaming in red. In response to their devastation at stopping her chemotherapy, I feel consoled by her terrible liver function, which precludes further treatment but also buys me time before discussing the inevitable.

2 days later, her husband says, "We are going to China." He adds, "There may be herbs we can try." I sidestep the implication that I have outlived my value. "It will be good for her to see her family." Tragically, her flight is cancelled when she becomes encephalopathic. It is but days between her last visit and her death.

Her husband is grief-stricken but also confounded. "But she has been like this for so long, I didn't think she was dying." At first glance, this curious comment could easily be construed as a form of denial. But on reflection, his lament seems just. She was young, brave, and willing to accept toxicity—talking up the prospects of a further chemotherapy regimen seemed easier than tackling the truly difficult subject of the end of life.



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Her goal was no different to anyone else confronted by a serious illness—to see the back of it. As her doctors, our goal was the same. But it became clear when her disease recurred that treatment would no longer cure her. So what was the correct time to check that she understood the difference between curative and palliative? When was the right time to broach a discussion that balanced idealistic hopes with realistic outcomes? Who should have had that discussion?

The corollary of telling the truth in oncology is said to be extinguishing hope. Those who train for years with the aim of banishing a disease do not want to be even remotely perceived as letting their patients down. Oncologists suffer genuine angst in losing patients, perhaps because we continue to lose them at such a high rate in comparison with our peers who have managed to turn former death sentences, such as HIV/AIDS, into chronic conditions. Of course, oncologists too can point proudly to some remarkable gains that have transformed the lives of patients, but the fact remains that cancer remains both a medically intriguing and emotionally eviscerating disease to contend with.

It seems logical that when our keen attempts to stave off disease fail, they should be matched by the will to ensure a peaceful and comfortable death. This in turn means finding ways of opening up difficult subjects with patients about topics such as limitation or withdrawal of treatment, desire for aggressive resuscitation, and choice of comfort measures. It is my experience that patients are initially apprehensive but almost always grateful for an opportunity to discuss their personal philosophy about life and death. Relatives often fret that such a conversation heralds the dashing of all hope, but I often find the opposite is true. People who have a chance to discuss their wishes for the end of life often die with less futile intervention and more meaningful input from those around them. Their relatives are also relieved to spend quality time with them instead of worrying about medical decision making. They tend to report less anxiety, stress, and depression in the aftermath of a death.

As populations become more educated and empowered, patients and their relatives are demanding more conversations with their doctor—the days of medical paternalism, at least in the west, are numbered. Simultaneously, clinicians are realising that such conversations are genuinely fraught and do not come naturally to most of us. After all, it is nicer to enthuse about vaguely promising data from a small phase I trial than to confront a favourite patient with her mortality. But communication skills can be learned and there is a growing interest in investing in quality communication skills programmes. In my hospital, surgeons, emergency physicians, and anaesthetists—not thought to be the traditional audience—are requesting formal training to help them navigate the changing demands of communicating with patients. They are realising that their own satisfaction and that of their patients is heavily dependent on the way they engage with each other. The hospital corporate counsel speaks at grand rounds to invoke the need for sensitive communication. This is a savvy move that highlights the devastating practical and financial consequences to the individual and the organisation when communication fails.

Now it is up to those responsible for medical education at every level to make room for such teaching by regarding it as a core mission of medicine and not an optional extra. Perhaps one way of accommodating this is by curtailing the relentless introduction of facts and statistics in the medical curriculum and paying more than lip service to nurturing aspects of humanity in medicine. Those in positions of influence must discourage doctors, young and old, from thinking that the art of medicine is useful only as long as science has not penetrated its way into the problem.

I wish that while my patient was still well, I and others could have encouraged her to think beyond the obvious but unachievable goals of being cured and living longer. Perhaps an opening could have come through the eager volunteers who help people put together photographs, videos, and letters. Or when she reported that her 6-year-old daughter wondered whether she could catch cancer in her sleep. When the task seemed too enormous to talk to her candidly about death, perhaps we could have looked for smaller windows into her thoughts. Of course, it is quite possible that she may not have wanted to openly discuss any of this with us, wary of signalling to us that she was giving up. But the devoted mother and wife she was, I can't help thinking that the reason she endured the rigours of chemotherapy was for her family's benefit. And the mere mention from us of examining her goals and priorities may have helped her make private sense of her illness and helped her refocus on the reality of the time she had left. She may also have seen our gesture as permission to discuss her fears. Instead, our silence made us complicit in the denial of these very natural concerns. It is as if we were not so afraid of dealing with her fears as of confronting our own impotence.

As I sign off on her file for the last time, I feel let down, by my actions and inaction. 5 years of preparation and yet nobody had a chance to say goodbye. I tell myself that the next time will be different. In search of the best cure, it should not be so easy to lose sight of good medicine.

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Further reading

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