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The “Authorized” Oncologist

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The hours after the surgery pass quickly, talking to the other patients. It is all very interesting, struggling with the drains hanging down on all sides, and then you wait for your hospital meals, which the family usually supplements during visiting hours in any way they can. We have stewed prunes for our digestion, good soup, fruit salad, the delights my family brings in large quantities. You are the center of attention and, although the faces are concerned, still a special kind of optimism reigns. The feeling that you no longer have any of the enemy in yourself is the most wonderful thing in the world.

A great deal of time will pass, over the course of many years of treatment, before I realize that every form of cancer, including breast cancer, is actually a systemic ailment, which occurs on the level of molecules. The doctors also serve to keep us in this wonderful ignorance. If you manage to catch them in a good mood on one of their rounds, you will only hear the stereotyped, melodically intoned sentence, “You are now a healthy woman, go on living a perfectly normal life.” I never understood who was lying here and why. But you accept that lie, gladly and easily, as the only possible truth. Still my inquisitive nature will not rest, so while I walk around the hospital corridors, I question a little the women who have already received that infamous PHD result (pathohistological diagnosis), while I am still waiting for mine. I “learned” that it is best if you have negative axilla, that this is the most important prognostic factor according to their criteria, that it would be really good if the tumor were hormone dependent to the highest percentage, because then, apart from chemotherapy, you have the option of hormone therapy. There was also some layman lamenting involved here. I felt like a hen pecking at corn on a rubbish heap, trying to collect as much grains as I could. She does it to fill her tiny stomach, but I do it in an attempt to put the pieces together in my brain, the pieces of my life, which had fallen apart in a moment. All of us were “encouraged” by the “truths” told by the doctors and our families, and you try hard to believe them when they say, “It will all be fine.” But in the quiet moments of the day, when the lively daily hospital ritual gradually eases af-

ter supper, I close my eyes... In my restless thoughts, the words from the poem “Just as Things Were” by my favorite poet, Desanka Maksimović, are all I can hear: “...and again in the evening everything in the room tells me of the thing that cannot be mended...”

Yes, that is the right word, the thing “that cannot be mended.” I am waiting for treatment, I have to get used to living from day to day, nothing is the way it used to be... All those stories about how life is in any case uncertain, how no one knows what to expect tomorrow, are simply not enough to prevent the tsunami in your soul, which threatens to overwhelm you, and those days you barely hold your head above water, while the doctors are mainly preoccupied with your drains, dressing your wounds, taking pictures of my silicon breast against the background of a green surgery wall. I thought then that this posing was only for professional studies and slides or presentations to students. As a university teacher myself, I had no objection.

And so I wait for my PHD, as some form of orientation in the therapy to come, but the very thought of possible chemotherapy makes the blood freeze in my veins. One afternoon, I was sitting on the edge of the bed of a Slovene woman called Bojana, the same one who had had the courage to come for a plastic surgery of her abdominal wall: “Bojana, I am so scared.”

“What of?”

“Of chemotherapy.” It was probably a childhood fear of being socially stigmatized. When you hear that someone is undergoing chemotherapy, you think he is probably done for, one foot in the grave, with no hope.

She took my hand and gently stroking my arm she said, “You will cross that bridge when you come to it!”

Don’t be afraid in advance. That became my mantra. Even today I use that sentence to comfort many of my friends, also patients, who, as they search the wilderness of the

internet in the middle of the night, send me e-mail messages about the breast cancer they have just had diagnosed, the operation they are to undergo, chemotherapy, radiation, side effects, tests, relapses, their fear... But what about our fears? Who is interested in them? They are what trouble us most and they are the hardest thing to cope with. Bad dreams, anxiety, depression, in the silence of the night of the sleeping city, counting the years of your child who is in school, then how many until the end of elementary school, then high school, then university, then the wedding... Waking before dawn, bathed in sweat, when again and again you realize that nothing is as it was, that it is not a dream, that this ugly thing is your reality, your life... – “and again in the evening everything tells me of the thing that cannot be mended.” Even today I repeat it in the flood of various fears, which I now call my “fearlettes.” In time, by using this diminutive they seem much less important and sometimes vanish altogether. The doctors who are supposed to give complete information about everything the patients want to know, have the least time and are the least prepared to prepare patients for all phases of treatment. That magical, prosaic sentence, “Think positive!” is supposed to be, I imagine, the solution for all our “fearlettes.” The only thing is, no one has taught you how to “think positive!”

For the rest of the afternoon Bojana told me about her expedition to Kilimanjaro as a tourist guide. Her picturesque description of distant parts brought calm to that anxious afternoon, somehow bringing me into a state of bliss, dreaming of travel to far off places and promising myself that one day, if not at the climbing stations, at least I would stand at the foot of that snow giant. I haven't yet. Recently in a New Year's letter I asked my friends if anyone knew if a person with a carcinomatous metastasis to the left pleura could climb Kilimanjaro? None of them probably even noticed that question or took it seriously, because no one replied. And what can anyone tell you about yourself? I have not yet visited the foot of Kilimanjaro, but I know I will. Because the one who succeeds is the one who thinks it can be done. That is the only true answer.

The PHD arrived. Tumor classification T2NOMO, hormone receptors: Er-O, Pr-O, HER 2 pos. (+++). Lymph nodes negative, 18/0. As far as I knew then, the status of the axilla nodes was the only positive thing in the prognosis. But everything else indicated an aggressive tumor. So, I had reached the bridge, now I was going to have to cross it. CHEMOTHERAPY. At the end of the discharge note it said: “Report to your authorized oncologist.” Who

was that? Where was my “authorized oncologist?” Oh, there where you find him. Whether on the recommendation of a friend, whether by reputation? Actually, in all the geographical areas of my homeland, in the generation I grew up in, here in Croatia, that means a “connection.” Shouldn't a patient, from the moment of the diagnosis, throughout the entire time of the therapy, in the phase of rehabilitative physical and psycho-supportive and later regular check ups, be covered as a part of an organized system? But if you are inquisitive like me, then even your “authorized” oncologist is not sufficient, you will certainly ask for a second, or even a third opinion. Those days I shuffled the pieces of my tumor and colored glass slides from hospital to hospital, desperately seeking an opinion that would save me from chemotherapy. It's only grade I, I thought, ignoring all the other characteristics of my tumor. And then an elderly, experienced pathologist resolved my dilemma: “My dear lady, you are young, you have negative hormonal receptors. That is not good. I have raised your grade to II, because you need to undergo chemotherapy.”

In the meantime the opinion of Prof. Claude Jasmin arrived; he was the head of oncology at the French Paul Brousse Clinic, Villejuif Clinical Protocol FEC 75. In relation to the recommended AC therapy, one more F therapy sounded to me, as a lay person, better, more sophisticated, like another ingredient in a good recipe, which would make the meal better, more tasty. Truly, if you see chemotherapy as a cookery book, everything is easier. I will never forget November 9, 2001, my first chemotherapy, just as I will not forget the horrible orange color of one of the bottles that were exchanged. Every object, drink, T-shirt, anything in a shop window in that color, still arouses in me the same association, the same metallic taste in my mouth...

Then followed 6 rounds of chemotherapy, and then radiation. And here I also acted on the opinion of the French doctors. I decided to undergo radiotherapy, although the opinion in Croatia was “radiotherapy is not indicated for now.” I do not know what had been better. I relied on my intuition. In a situation when in any case no one can guarantee anything, intuition is the only thing you have left, which gives you a form of internal confidence that you are doing the right thing for yourself, the best you know. The prescribed 25 sessions of radiation took 52 days. The machine broke down twice, with pauses of 12 days, and due to the silicon implant the surgical scar was not additionally radiated with the usual final increased dosage, what they call the “boost.” Later, Prof Jasmin, whom I visited at the Villejuif Clinic in person due to a local relapse along

the surgical scar in 2004, stated in his report: "radiotherapy of 52 days was not undertaken in an appropriate manner, that is, it was performed under poor conditions."

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The HERA clinical trial begins in Croatia. They know of possible side-effects, while the potential benefits of the adjuvant immunotherapy for HER2 positive breast tumors will only be seen over the next 5-7 or more years, as is always the case with new therapies. I go for an interview because of possible inclusion in the trial and wait for randomization. No one can tell me what to do, because no one knows. At the same time, on the pages of the Food and Drug Administration there is a serious warning that this drug which is extremely cardiotoxic. To my timid inquiry of the doctor how far my heart is really threatened by that therapy, I received the reply that we do not have time for stupid questions!

"My dear, a STUPID question?!!" I repeat in myself as I swallow the lump in my throat, holding back my tears.

"Would Prof. Jose Baselga perhaps know the answer to my question about the possible effectiveness of this new immunotherapy and about whether it is cardiotoxic?" I do not give up!

Prof. Baselga from the Vall d'Hebron University Hospital, Barcelona, is one of the 5 leading names in the world for breast cancer, a clinician and scientist. In 2002, he treated more than 6000 women in a single clinical trial.

"Do you really think Prof. Baselga would have time to answer a question like that by e-mail?" the raised eyebrows and mocking smile on the doctor's face spoke for themselves.

To my inquiry by e-mail sent to Prof. Baselga on 1 July 2002, late in the evening, I received a reply in less than 12 hours, and I give it here in full: "Dear Vesna, I would not use Herceptin in your case. You had a lymph node negative disease and since your tumour was HER2 positive, it may have benefited more from FAC. There is no data on Herceptin in the adjuvant setting and I would just not recommend it outside clinical trials. It may have serious adverse effects and we do not know about benefits. Best regards. J.B."

Of course even Prof. Jose Baselga, to whom I have been going for 5 years now twice a year for check ups and consultations, is not David Copperfield and cannot make an illusion out of reality, but in his approach, to the patient, he has

unlimited optimism. During my last visit, I was extremely concerned about a new situation that had occurred, which the Professor resolved in one sentence, "Vesna, you can live many, many years with good therapy! Please stop measuring the size of your lesion in millimetres, you will drive yourself mad. Start enjoying life!"

"Thank you, professor, I am really feeling down and out at the moment. I actually came to Barcelona just to hear that sentence."

A firm, encouraging hug, a friendly kiss, and the expression on his face when he was talking with me are enough for me not to doubt for a moment his recommendations and his words. I send all patients from Croatia who want a second opinion abroad to him; he has several patients from Croatia who go to him regularly for check-ups.

Despite the successful inclusion in the study for 2 years, in 2002 I refused to be part of the HERA trial and decided to consider my treatment complete. Several months later, more precisely on September 14, 2002, as I was drinking my morning coffee and leafing through the daily newspaper *Večernji list* on a Sunday morning, my husband suddenly cried out, "Hey, your picture's in the paper!" I thought that I had parked badly again, like many years ago, when the photograph of my car was published on the front page of a newspaper with the heading "A Wagon on Zrinjevac." As I was late for work I had arrogantly parked on the pavement on Zrinjevac and someone found it interesting. But this time the heading was truly bombastic, "Feminine Despite Surgery!" On an entire page of *Večernji list* there was a picture of my breasts after the surgery, my two moles in the middle, one under the other, absolutely no mistake, this was my photograph from the hospital. My husband tried to ease my shock and horror, "Don't get upset, there's no head, no one knows it's you!" What! Like all that was needed was to include my head! I KNOW, that is what is important for me. I thought I had my picture taken for their textbooks, and not for 4 million Croatian citizens. That day was what they call a crying day. It required an incredible nerve and was a serious ethical violation. Didn't they have a record of the patient's name by each slide? They should have informed me and asked my permission to do something like that.

Are we really deprived of any identity for the "white elite?" Am I truly in this case nothing more than a sample of their successful esthetic work, FEMININE despite surgery?