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By Vesna Andrijević-Matovac
vesna.andrijevic-matovac@zg.t-com.hr

"Why Patient Voice?" some of my friends asked me after they read my first column for the *CMJ*. One even said jokingly, "Hey, you are always so loud and aggressive. Who wouldn't be able to hear you? Why don't you write about something we don't know?" He was referring to our student days, when we were hanging around as singles; later we managed to keep our friendship going including our marriage partners, first our children's birthdays, then the adults' birthdays, we never missed an excuse for a party. They knew everything about me, and the main target of their teasing was my hypochondria. I had undergone every test known to man, the range of diagnoses was truly imaginative, all kinds of exotic diseases. So they soon dubbed me "the best lay doctor" ever.

THE DIAGNOSIS – OCTOBER 9, 2001

I came to the clinic early in the morning. I had a mammogram done, which was supposed to further confirm the diagnosis of breast cancer. I waited, endlessly. There was still hope. No fear, no thoughts, mental anesthesia.

The nurse took me into the empty surgery and gave me brief instructions:

"Strip to the waist and lie down here, please!"

"Another ultrasound! I had one yesterday!" I started to protest, while she, silently went on with her job.

A young, good-looking doctor came into the surgery with a white entourage in tow, consisting of doctors, men and women, and what I later learned, students and interns. He started the repeat ultrasound examination, some of them looking in wonder and feeling my breast, commenting to each other and the students, while they passed my mammogram picture from hand to hand and compared it with what they could see on the ultrasound screen. The needle aspiration biopsy was to be repeated! There was no more hope!

"Have I come in time?" I asked. No reply.

"Look, a young patient, there are absolutely no signs externally on the breast, the nipples are not inverted, there is no discharge, the skin does not look like orange peel….!"

I DO NOT EXIST, BUT THEY ARE EXAMINING ME, I AM NOT IN THE ROOM, BUT THEY ARE COMMENTING ON MY CASE, NO ONE IS TALKING TO ME, NO ONE IS TELLING ME ANYTHING, NO ONE HAS TOUCHED MY HAND, LOOKED IN MY EYES… At times like this, even the touch of a stranger would be a comfort…

"Have I come in time?" I asked again, louder this time.

"Are you a doctor?"

"No, I am an assistant lecturer at the Economics Faculty!"

"Aha!" The tone of that "Aha!" translated meant, "There is no point in wasting time explaining, the patient is not a doctor, she has no idea about medicine…"

It was soon all over, the white entourage moved to another bed behind a screen and the good-looking doctor, just quickly and a little absent minded, remained for a moment beside me and handed me the mammogram picture, "Mrs Andrijević, you have breast cancer. Report to the surgeon to arrange an operation! It is best to get it done here by our plastic surgeons. They do a good job here."

"CANCER?! Two days before I had handed in my research for my doctor's thesis, my daughter is eleven years old and my whole life is before me. HOW MUCH CANCER, WHAT KIND OF CANCER, HAD I COME IN TIME?!!!" – the unanswered questions screamed out inside me.

There were two pairs of concerned eyes waiting for me outside, my father and sister, herself a doctor, an ophthalmologist. Although five years younger, she had always been the older sister in our relationship, always my support and comfort.

“I’VE GOT CANCER! I’VE GOT TO HAVE AN EMERGENCY OPERATION!” I didn’t have the strength to look them in the face.

There is time well used, and there is wasted time… I remember my mother’s words, when I was a student and I was doing something other than what she thought I should be doing. She would say, “Vesna, why are you wasting time on something so stupid?” But what is ”IN TIME” when it is a matter of a timely diagnosis, who actually knows? I had learned there are good and bad factors for a prognosis: a tumor less than 1 cm, negative axilla, hormonal dependence desirable, HER2 expression –better not, better that you are older and in menopause, etc. etc. All these are statistics, and statistics is a wonderful discipline, with which you can prove everything and disprove anything, it is only important to have a good hypothesis. Here, “IN TIME” is not measured in units of time, but in millimeters in terms of the size of the tumor, at least according to “evidence based medicine.”

But today, I know that they could not have given me an answer because they did not know, because “the good prognosis factors” in reality are actually not critical. And they didn’t know how to tell me about my malignant disease in a more appropriate, humane way because they had never learnt how. In the syllabus of the Medical Schools in this country, there is no systematic education about how to communicate with patients, especially how to tell patients something which will forever change their lives. This October, our Association “All for Her” (*Sve za Nju!*) launched a small handbook for patients and their families, “Emotions and Cancer – What About When Your Soul Is in Pain?” We wrote it together – experts, psychiatrists and patients, and we are sending it these days to all oncology wards, to all patients who have asked for it, to associations dealing with this issue, and which makes me especially glad, to diagnostic institutions, surgeries, and polyclinics, because they are most often the first places where people learn that their lives have been hit by a natural disaster. The written word will never be able to replace the touch of a hand, a squeeze as a sign of support, a sympathetic and understanding look, and an explanation worthy of the exaltedness and humane nature of the medical profession. But I would have liked, in those first moments and days of the process of facing up to and accepting the diagnosis, to see something else in the oncologist’s waiting room other than advertisements for drugs from the pharmacological industry or information about where you can get a quick short-term loan. Two years later I realized that these little fliers about loans, which someone put in the oncology clinics, also had a purpose.

I arranged an emergency operation by the plastic surgeon for the October 15. Indeed, it could not have been sooner. All those five days, the inner family council was constantly in session, my husband called it the “brain trust.” Radical mastectomy, quadrantectomy, reconstruction of the breast, this way, that way, from back muscles, from the stomach, the buttocks, and maybe later even a nipple, first a tattoo, then if you want, from… oh man, it is hard to believe how far medicine has come. I couldn’t listen too much to what they were talking about, I still had five days to the operation, it felt like five centuries, in which I would learn everything, find out about everything, make a wise decision, and what I didn’t know, I was sure my surgeon would let me know. The phones rang, everyone was very well-meaning, they wanted to help. But, the actor in me was coming alive, the one who failed twice to get into drama academy, seeing the paradox from Brecht’s “Mother Courage.” In the center of attention, I finally had a real diagnosis, which as it happened was not one of those from my hypochondriac collection. And everyone was concerned, because Vesna talked endlessly about her sideropenic anemia or vasomotor rhinitis, her twice normal cortisol levels, which never had had a confirmed cause, about many symptoms which were all lumped together as neurovegetative dystonia … “How would she be able to cope with a serious, real diagnosis like cancer?”

FIRST OPERATION – RECONSTRUCTION?

I am early on the schedule. They bring me a white, ripped shirt, which ties at the back. A nurse comes with the premeds. I am terribly afraid of anesthesia, allergies, anaphylaxis. All in my family are bronchial asthmatics, so that is an additional phobia. I wait for my surgeon impatiently. I have no idea about this notorious breast reconstruction, which they say is so important for the psychological post-operative recovery of women. The trend in the world is for the woman to wake up with a “new breast.” This reminds me of “lost and found.” What? A woman with two breasts is a woman, and if she loses one of them, she no longer is? I disagree. My personality and I consist of much, much more than a piece of tissue. I feel like a down and out, waiting there, sitting in that shirt, on the edge of the bed. Finally my doctor, coming in like a whirlwind, with rapid movements sits down beside me.

“So, let’s see, there’s nothing here?!” he says, touching my back…

“A bit here…” he touches my stomach…

“So, we can reconstruct your breast from your stomach, you are thin, you don’t have a lot of fatty tissue, but you don’t have large breasts either, so it will be good.”

“How long does the operation take?” I ask, a little woozy from the pre-meds.

“A few hours.”

“Listen, there is no way you are going to do that,” I am now already angry with myself, because I can see myself going into surgery not knowing anything. I don’t want other parts of my body to be cut so I can have a “stomach-breast,” while at the same time I have an uninvited guest inside, an intruder, who is threatening to kill me. I decide in a moment.

“Professor, the only thing that I may possibly allow, is a silicon implant, which you mentioned…!”

A conversation of a few minutes was not enough to learn all the shortcomings of silicon implants, the problems that may arise – that in the end it was a “spare skin mastectomy” and not a radical one, that due to an implant the radiation might not be as it should be, so as not to damage the implant etc. etc. During the operation I suffered a pneumothorax (my God, all kinds of things can happen during surgery), and in order to save skin, the intraoperative PhD says, “The tumor reaches to the edge of the resection.” That is not bad luck, that is not “well, a bit unfortunate.” That is giving insufficient information to the patient, who is not able to inform herself about it all, and who received no or incomplete information from her doctor.

ADVENT 2009

I look this evening at my beloved Zagreb, adorned with thousands of tiny, twinkling decorations. Imaginative shop windows, but for a long time I haven’t needed anything from any of them. Because what I need doesn’t have a shop window, it can’t be paid for in cash or even with the credit cards we women love so much. I am thinking about what I am going to wear tomorrow. In the Mimara Museum, the presidential candidates are taking part in a charity event to raise money for a new machine for early detection of lung cancer. These days a few of our associations founded the Federation of Oncological Associations called “Together against Cancer,” united by the same mission and vision, aimed at improving all aspects of the treatment of patients with malignant diseases. If patients don’t know something, they should ask. If patients have doubts, they should ask for a “second opinion,” without fear of what their doctor will say. Moreover, patients should even be able to go over and discuss that “second opinion” with the first doctor. Patients should not just be listened to. Patients should be heard. That is the reason for my “Patient’s Voice:” in doctors’ surgeries, in patients’ associations, in Parliament. No one can pass a law relating to us without listening to us and hearing us.

Another Christmas will soon be here, one more birthday for me. What did my question mean about the diagnosis, “In time”? My years are lining up, like the gingerbread hearts I will use to decorate our Christmas tree on Christmas Eve. My friends stopped talking about my hypochondria long ago. It doesn’t matter that I failed the entrance exam for the drama academy twice. Suffering can teach you a great deal, and it has given me insight into my real ability, I have learned a great deal about myself. It has shown me that I can play “Mother Courage” in real life with the best of them. Because it doesn’t matter how much time you will have, but how you will use that time in the best possible way. *Carpe diem*, breathe deeply every moment you have.