doi: 10.3325/cmj.2010.51.563

The Light from Bethlehem

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Dear readers of the *CMJ*,

We are coming to the end of another year, in which I have tried to tell you about the highs and lows of my ten years of treatment for breast cancer... Since a dear friend spontaneously described my columns as a "never-ending story," I will be glad to continue to share my story with you in future issues, but allow me to dedicate this essay to my young colleagues who died this year – women who had been undergoing treatment for many years, just like me. Although we were not close friends and we did not spend time with each other's families, people like us, sharing faith, hopes and fears, and optimism, become close, just like war veterans. As I write this I am myself at the cardiology department of the hospital center because of a pericardial effusion, probably post-radiation, after treatment of my pleura in Munich this summer. The view from my window is over Kišpatićeva street, over the whole of Zagreb. Although the view of Zagreb "in flames" of the setting sun was idyllic for the past few days, this evening I cannot summon up anything even close to that idyll, there is a southern wind (*jugo*) too warm for December... heavy, gray clouds dragging themselves across the sky... And I remember the time we spent together in Barcelona, our joy at the remission of the disease, ice cream, and coffee on sunny La Rambla...

GOGA (49)

Message: It's sunny outside...

I met Goga in 2003, when she underwent her first operation. I referred her to Prof. Baselga in Barcelona, for a second opinion. Later she continued in Aviano with Prof. Veronesi, due to some clinical studies she was included in.

In the autumn of 2007, the three of us, Goga, Andrea, and I went to see Prof. Baselga for our usual check-ups. We had fun and spent three days shopping. Goga and I slept in a hotel near La Rambla. She was angry because we had found such an expensive hotel, which was actually terrible, but that is how it always is in Barcelona in the tourist season. But it was October. One evening, late at night, we couldn't sleep, so we told stories of our student days and she told me about how she was co-owner of a company which her partner tried to exclude her from in any way he could as soon as she became ill. We laughed like crazy, as loud as high school girls. And then she suddenly burst into tears and said that she was missing her husband Zoran terribly. From the conversations we had those three days, it was clear what an enormous support her husband, six years her junior, had been to her and how strong their relationship was.

She went through all the chemotherapy protocols, Fac, Taxol, Herceptin, radiation, Gemzar, Navelbin, Xeloda, Lapatinib. Unfortunately, nothing could stop her illness.

I lost contact with her over the last year. She narrowed down her circle of contacts, closed in on herself, wanting to spend all her time with Zoran and their ten-year old son, Adrijan. As Zoran is the physiotherapist of Croatia's top sportsman, Ivica Kostelić, she traveled a lot with him and was out in the fresh air as much as possible.

I was never able to make her join the work of our patients' association "Everything for Her!" or to take part in some of our activities, she simply did not accept that form of struggle, that was not her way. When I found out the day before that our joint doctor and friend Prof. Brkljačić was going to visit her, I asked his wife, Dijana, to tell her that Andrea and I love her and that we are praying for her. Dijana told me that Goga was at home, weighing only 40 kg and having a nasogastric tube inserted since due to metastasis on her brain she could no longer swallow and was very weak.

That same evening I unexpectedly received a text message from Goga, as follows:

"I am trying to write a text message. I am more active. Call me because then I am not dependent on another person or the computer. Help me, this is my cell phone!!! Goga S.P."

A few minutes later I received the following message: "Vesna, I only have Dr. Braš' e-mail. Can you send her an e-mail: Please help me. Goga S.P."

I wrote right back to her: "My Dear, have you got the strength to talk if I call you?"

"Try!"

I called her straight away. I could hardly hear her....

"This is as loud as I can," she said in a quiet whisper, and I automatically started talking quietly too.

"You don't have to whisper..." she said...

She described how she was.

"Please, send me a text message... I will read it if I can. Write something to me."

"Goga, you know, Andrea and I were desperate because we couldn't get to you for a year..."

"Don't be afraid and don't cry. Tell me... just send me messages and I will fight for all of us girls. We are brave girls. I've bought a wheelchair too, so I can get out when the weather is better."

"Do you want me to send you an e-mail?" I asked her.

"No, I don't like e-mails, because then I have to depend on Zoran, but if you do send a mail, write in big letters and send a text message: "Goga, I sent you an e-mail" and I will read it when I can."

"Do you want us to come and see you, Andrea and I? I've got a virus right now, but when I get better?"

"I am so tired, I fall asleep, just send me messages please..."

"What do you want me to write?"

"Write about what you're doing, write to me: 'Goga, it's sunny outside, this is what I am doing'... whatever..."

"OK, I will write what we are doing in the association and how our pioneer work is going..."

"Good, you know, I have some paper by my bed, because I forget everything..."

"That is because of the radiation to your head, dear, but it will get better when that swelling on your brain goes down..."

"Have you heard of the Bob Beck protocol? It's some kind of alternative way to treat cancer, using some methods they are not allowed to use in official medicine," I asked her, "I'm thinking about it..."

"Write to me about it and I will read it..."

Her whisper was getting quieter and quieter; I felt I had to end the conversation...

"Vesna, when are we going to go to Barcelona?" she asked me, I choked on my tears, but I didn't want her to hear... I remembered how, on a late night flight from FFM-Barcelona, we sang a song by Jadranka Stojaković together... "We could have done anything, if only the day had been longer..."

"Goga, as soon as the weather gets better... in spring..." I put down the phone and wondered, "Oh God, is there somewhere a city as beautiful as Barcelona, somewhere in heaven?"

There was nothing so hard for me, in the eight years I had undergone treatment, nothing so loud as Goga's whisper: "**JUST SEND ME A MESSAGE!**"

That same evening I sent an e-mail to everyone, those who knew her and those who didn't, "**Please, from tonight, send her at least one message every day**. Let's not let her feel abandoned and lonely for even a minute. Zoran is with her 24 hours a day, but she needs the rest of us too, who are going through the same thing, or have gone through it. Let's not write pathetic messages. Write ordinary messages of support as you are inspired but if you are having a hard time yourself, don't write anything, just pray that God will give her strength for what she is going through. I will personally send a request to the nuns I know to pray for her. All we can give her now is to express our love and support in the way she asked for herself: **HELP ME! SEND ME A MESSAGE!**"

Goga left us after a few days, on the January 25 this year, and her cell phone was left full forever of unread messages of support and love...

ANDREA (38)

I met Andrea in 2005. She was bright, cheerful, smiling, and optimistic. She was doing really, really well right up until spring this year, when her illness suddenly got worse, with an effusion of water in both her lungs. Since I was in Munich myself receiving radiation treatment on my left lung, she came immediately to Munich with her husband and for two months did all she could to stabilize her condition, but in her case, Prof. Molls from the Clinic Rechts der Isaar was not able to use radiation, but only systemic therapy, which she underwent in Zagreb... After than she lost 20 kg and never really recovered...

Wednesday, November 3, 2010

Our association's secretary, Tomo, called me from our Center for Psychological Support to tell me that Andrea needed me urgently. She asked for someone to come from the Center because she was going to jump out the window or break everything in the house... She was terribly afraid and panicky. The duty psychologist at the Center thought she was in a very serious state, and talked to her on the phone, while the woman who cooked for her family held her hand. At the same time, although she had called an ambulance to come to her house and possibly give her something to calm her down, the doctor simply told her to see her family physician and put down the phone.

Thursday, November 4, 2010

Andrea called me again. She doesn't want to go to hospital. No way. But she wants something to calm her down again... Her mother brought her anti-depressants from the doctor, but we know it takes at least 10 days for those antidepressives to kick in...

Friday, November 5, 2010

Andrea calls again. We know that our Center for Psychological Support for women suffering from cancer is not competent, in terms of expertise or staff, to offer support of this kind... but we do all we can to try to help somehow. I called Dr Marijana Braš, the president of the Croatian Society of Hospice and Palliative Care, not knowing she was in New York... I wrote her an urgent message...

"Dear Marijana,

I've been calling, but the telephone rings as though you are abroad. Please reply as soon as you read this mail. Andrea G. is really in a poor shape, she can't get out of bed. I think she is terribly depressed, and is having panic attacks. The other day, we had a therapy session with her over the phone from the Center, but she also needs pharmacotherapy. Dr Curać, the psychiatrist, advised her to start taking Zoloft immediately, but because of its slow effect, she is not happy, so Dr Gruden prescribed 4 × Lexaurin of 1.5 mg as first aid over the phone, which nearly finished her off because she has lost more than 20 kg and is very weak.

Although the CT of the thorax showed that the water has gone and there are no new lesions, her lack of breath tells me the state of her lungs is not good, but it could be a combination of the depression and the terrible cachexia she has got into."

I called Dr Veljko Đorđević in the hope that at least he was in Zagreb. Veljko picked up the phone and told me that he was also in New York. I thanked him, because people don't usually pick up once they cross the Slovenian border, because of the price of roaming calls... then I wrote more e-mails to Veljko and Marijana....

"Please reply to me from NY – is there any little team with a psychiatrist from the Croatian Society for Hospice and Palliative Care whose president you are, who could help visit this patient with me?

What should we do with patients on the ground until institutions for palliative care finally come down from the academic level to the patients in the true sense of the word, on the ground, in the way Mother Teresa did it, day after day?"

"Dear Vesna,

Greetings from NY. We are at Memorial about to learn about how to teach oncologists communication skills.

I am aware of everything you say and I agree with you, the only problem is that we are only just now trying to do something on that academic level and we haven't managed in 16 years to break through to the clinical level. Everything is still up to the work of non-governmental agencies." ("Which NGOs???" I asked myself as I read this)

Saturday, November 6, 2010.

Early morning, Andrea called me again in the middle of a terrible panic attack.

The only thing I could do was call my psychiatrist colleague, ask her to get a taxi, take the bill to the "Everything for Her!" and to offer psychotherapy. She told me herself that this was beyond the bounds permitted by the Croatian Medical Association but still at my request, as a psychiatrist with many years' experience, she went immediately to the address at Bijenik and did her job.

In our last telephone conversation that afternoon, she told me:

"I love you, I love you so much for sending me your colleague...."

She died two days later, on the November 8, 2010, at the age of 38, and she wanted to go in her wedding dress...

Someone told me that her wish was grotesque... but that "someone" has no idea what it means to remember one of the happy days from one's younger life, deeply aware that you are leaving, going to face something completely unknown, which scares you so deeply...

Is it not much more grotesque that our Center for Psychological Support, those last few days of Andrea's life, "played at" being some kind of team and tried to help the best we could with the psychologists and psychiatrists available? Isn't it grotesque that we are the last country in the region which does not have palliative care built into its health care system, despite the dedicated pioneer work of Prof. Anica Jušić, who gave her personal contribution by working with terminal patients for more than a decade?

LIGHT A LAMP TOO…

Recently, a Center for Palliative Medicine, Medical Ethics and Communication Skills was opened at the Zagreb University School of Medicine. A gala charity dinner was held with the basic aim of equipping the Center. As an NGO we were invited, but of course we had to find someone to pay for the table for us and make a donation to set up the Center... We were glad to help, found a donor, and prepared a short 10-minute film about our member Branka Smolčić who has been fighting breast cancer for more than 10 years, but for the last two years has been completely bedridden due to metastasis on her brain and is completely dependent on her husband. I have her listed in my cell phone as "*Branka the indestructible*"...

Although the organizers, in their schedule for the evening, had planned time for our organization to be heard... unfortunately we did not have the chance to talk about these three families, who are in fact a reflection of the state of our country. Mr Peršo, the private physiotherapist of our top skier Ivica Kostelić, was away those days, but he wrote the following to me on the day of the charity dinner:

"Dear Vesna,

It is hard for me to say something sensible after everything. Even if organized palliative care and a five-star hospice existed I would have taken Goga home. She died in her own bed, clean and as far as possible without pain. Since she was completely unable to move, I turned her every hour or 90 minutes, day and night, so we avoided bed sores. Also, literally right up to the last day I took her, that is, I carried her to the toilet and bathed her in the bath. When she didn't have enough strength I would wipe her in the bed. She ate right up to the last day. Since she couldn't swallow, I fed her with a tube on liquidized food. I gave her an infusion every day and medication intravenously. Ana from Hematology changed her needle about every seven days because it was really hard to find a vein, and Dr Ajduković also came with her very often.

She loved me to read to her and she loved to hear about what was going on outside. She was bright right up to the last day. That day, the January 25, at 2 in the afternoon, our son and I were with her, watching her last breaths. We dressed her by ourselves for her final rest.

Of course this is impossible for most people, even with the best will in the world. I was able to leave my work and be by her bedside, and I knew enough to at least try and ease that terrible suffering. She died surrounded by her family and she was aware of that.

So much for now.

A big hug for you all.

Pršo."

Yes, those three families, those three dedicated husbands, Zoran Pršo, Krešo Gulija, and Bobo Smolčić, first of all had the knowledge, financial capacity, and most of all the love to take care of their wives and do what should have been built long ago into the system of care for seriously ill patients.

The creator of the term "palliative" was Dr Balfour Mount, a Canadian. The word has its origin in the Latin term "pallium," meaning a garment used to protect people from the cold. The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families when dealing with problems arising from terminal illness. It alleviates and prevents the suffering by providing early and correct diagnosis and treatment, and deals not only with pain but with other problems –physical, psychosocial, and spiritual.

At the Parliamentary Assembly of the Council of Europe on November 4, 2008, Wolfgang Wodarg, a German from the socialist group, gave a report (CEE&FSU NEWSLETTER, Vol.V.No.1 January 2009), which mentions in its references the article by Anica Jušić Palliative Care – a Model for Reform of Health and Social Policies. Author's Review (1). The author looks at palliative care as an important component of applied health care, founded on human dignity, autonomy, human rights, the rights of patients, and the generally accepted perception of solidarity and social cohesion. Medicine should be oriented to the person as a whole, including where necessary social, psychological, and spiritual assistance, which may for some patients be more important than medical care in the narrow sense.

Therefore, the association "Everything for Her!" for women suffering and recovering from breast cancer, their families and friends, congratulates all those who took part in founding the Center for Palliative Medicine, Medical Ethics and Communication Skills, which will one day certainly become an educational center of excellence for young generations of medical students. We hope to establish a close collaboration with the Center, primarily for the education of the leaders of our supportive workshops for women. Anica Jušić, the leader of palliative medicine in Croatia, says that the term palliative care is usually used when referring to a multi-professional and multi-disciplinary team approach by physicians, care providers, social workers, physical therapist, psychologists, and spiritual care providers (2).

We therefore expect all the competent institutions in Croatia to organize immediately multidisciplinary expert teams for palliative care, who, alongside the Center for Palliative Medicine, Medical Ethics and Communication Skills, will begin to act in the community...

I am not asking for this because the Republic of Croatia, in Chapter 19 of its accession report, assumed the obligation to report to the European Union on the availability of health care for groups especially at risk, and hand in "a report on the availability, quality and sustainability of the provision of palliative care in the Republic of Croatia and the possibility of its evaluation."

We are asking this so that all those competent and responsible in Croatia finally become a part of OUR STORIES, but not when illness comes to them or someone they love, when they suddenly become very sensitized; but as healthy and, above all, responsible individuals who want to do something about the fact that Croatia is the only country in the region that did not long ago develop care for the seriously and terminally ill as part of its health care system. So the patients are left in the end to their families, which become the only donation oasis to make possible for their loved ones to have a more or less "gala" end to their earhtly path.

We are not interested in whose fault and disgrace these failures are... We only want, as a part of the civil society, to light a lamp on our way... Zoran, Krešo, and Bobo each lighted that light of love and care in their own ways... Ladies and gentlemen, light a lamp yourself too, just like the light from Bethlehem that we wait for at this time of year...

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