



Snežana M Bošnjak – Girl On Fire

*“To lead, you must: get beyond yourself, grow beyond yourself,
give beyond yourself, go beyond yourself.”*

John C. Maxwell

My leadership journey began in 1992, when I started working at the Institute for Oncology and Radiology of Serbia (IORS) as a junior physician specializing in clinical pharmacology. I was attracted by the intensive development of new medicines in oncology. However, everything else related to oncology was not attractive. Oncology was stigmatized at that time as a dreadful discipline, full of agony and death. People even used to cross to the other side of the street when passing by the IORS building.

At the IORS, I finished my specialization with a Master’s degree and PhD in oncology. My current work at the IORS is dedicated to the integration of supportive and palliative care in oncology. My vision is that every patient and the family will receive the support and care they need to live with cancer and cope with its treatment.

Chemotherapy without vomiting

When I started working at IORS, I was already writing my Master’s thesis on the prevention of nausea and vomiting induced by chemotherapy. Although I had read many papers about that problem, IORS was my first contact with its impact in real life. Next to each bed was a plastic bowl for vomiting. Every time I entered patients’ rooms, someone would be there vomiting. It was very uncomfortable for me to see patients suffering so obviously from the treatment, from something that was supposed to *help* them. Moreover, I recognized that patients were

convinced that vomiting was acceptable and even required, like *an evidence* that chemotherapy was working. I had to explain that although anticancer treatment is required to be aggressive, the toxicity is not acceptable and we should do everything to minimize it.

I knew that vomiting could be prevented with the proper use of medicines and I started applying antiemetic protocols I had been reading about. Once this treatment proved to be successful, colleagues started to invite me for antiemetic consultations. Many years later, one nurse said to me, “When you came to the hospital, the vomiting bowls disappeared.”

That is how I became interested in the field of prevention and treatment of toxicity induced by anticancer treatment. This was an unexplored but critical issue for patients and, with my previous knowledge of medications, I was in a position to help. I started looking for information and found it in the *Journal of Supportive Care*, the official journal of the Multinational Association of Supportive Care in Cancer (MASCC). MASCC membership brought me in contact with colleagues who shared my interest and helped me obtain the information and support I needed.

Cancer without pain

At that time, patients used to think that cancer must be painful and they accepted suffering in silence. It was so sad. It was unbearable. I strongly believed that there must be a way to relieve the pain. I had a knowledge about the use of analgesics, so I offered my help.

At the time tramadol was the most widely-used prescription. Simply by implementing basic principles, like using it by the clock instead on demand, giving it by mouth instead of injection, and titrating it to the needed dose, proved to be very effective. Patients previously in agony greeted me sitting in bed and with a smile. They told me that they finally had a good night's sleep. Women took care of their hair again and put on make-up. Everyone's morale, including mine, improved in a day! This was so gratifying.

When sustained-release morphine tablets were registered in Serbia, I was invited to give a lecture on the role of morphine in cancer pain management. I was given Robert Twycross' book to help me prepare. It captured me completely, challenging many concepts I had learned at Medical School. Twycross presented morphine as the key indispensable analgesic that can be used in *every* phase of the disease without major contraindications and dose restrictions. My favorite quote from the book is, “Strong opioids exist to be given, not merely to be withheld; their use should be dictated by therapeutic need and response not by brevity of prognosis.” I still quote this for advocacy.

We had learned in medical school that morphine was a dangerous medicine to be avoided due to its potential to create addiction and induce respiratory depression. My textbook of pharmacology said morphine should be used like Uncle Scrooge spends his gold!

The IORS already had an outpatient service for cancer pain run by anesthesiologists. I joined the service and started to use morphine for all patients with severe pain, including those still receiving anticancer treatment. This was quite revolutionary. The IORS had morphine solution but it was given only to dying patients. My next step was to initiate cancer pain consultations for hospitalized patients and promote cancer pain assessment and optimal treatment for every patient.

Symptoms as diagnosis

When the IORS decided to translate the World Health Organization (WHO) books on the management of cancer pain and symptoms of terminal illness, I was selected to be one of the translators.

These two books opened a window into the world of symptoms for me. I realized that symptoms themselves could be considered as a diagnosis deserving proper evaluation and treatment. This was not the way we had been taught medicine: symptoms had always been only a part of a certain disease and were treated as such.

I was struck by many details showing concern and care about patients. For example, I read that a patient vomiting blood should be given a red or blue towel instead of a white one. They thought of everything! Naturally, patients would be terrified seeing their own blood on a white towel! These WHO books showed me how cure should always include care.

Treat the whole patient and not just the disease

My initial impression at the IORS was that the patient was not visible enough, and was seen almost like a carrier of the tumor that may or may not be cured or reduced. I wanted to change that culture. I felt that we needed to see and hear our patients. Although the ultimate goal in oncology will always be to prolong life, we also need to bear in mind patients' symptoms and the toxicity of anticancer treatment.

The art of oncology is to treat "the whole patient and not just the disease" (Vardy J, Tannock IF).

When the IORS opened the Oncology Intensive Care unit for phase 1 clinical trials in 1994, I was assigned to the service. For me, this was an opportunity to show what could be done to control the toxicity of new medications. Over time, oncologists started to refer patients with severe cancer symptoms for intensive care as well. In 1999, I was appointed as the chief of the unit. Under my influence the service gradually evolved towards supportive oncology unit. Now the unit actually works exclusively for supportive and palliative care! We have 4 beds.

Get the message across

The breakthrough came when Dr. Snežana Šušnjar joined the intensive care unit in 2000. As a medical oncologist, and later as chief of the unit, she helped the team get the message across to other oncologists. She became a passionate promoter of bridging supportive care, palliative care and oncology.

More and more frequently, we were asked to do consultations throughout the IORS. I always went accompanied by a nurse. The idea behind it was to educate the nurses who, at the beginning were my greatest supporters and co-workers. Let me mention here nurses Dusanka Živković, Zorica Marinković and Natasa Bakić. We were like a “mobile consulting team” -- a kind of work not common in our Serbian hospitals where, traditionally, work is not interdisciplinary.

After consultations, the nurse would stay longer to clarify the treatment plan to the patient and the nurse in charge. Because our hospitals house many patients in one room, a single consultation was an effective way to raise awareness among other patients about how our discipline worked and how it might also help them.

Go beyond traditional physician role: the First International Symposium on Supportive and Palliative Care in Serbia (2004)

In 2003, the European Society of Medical Oncologists (ESMO) took a stand on supportive and palliative care and published the following statement:

“The goals of oncology can no longer be limited to the reduction of tumor burden and the deferral of death, but must also include preservation and improvement of patient’s quality of life across the entire continuum of the cancer experience.”

ESMO, 2003.

Inspired by the ESMO statement, I proposed organizing the symposium exclusively on supportive and palliative care. IORS accepted my proposal. The goal of the symposium was to shift the focus from disease to patient-directed topics, and the patients’ right to have the best possible quality of life.

This called for me to step out of the traditional physician role and deal with all the issues related to organization, promotion and funding of such an event. I developed media contacts and for the first time appeared on TV, wrote press releases and organized press conferences. Wishing to motivate and inspire the audience with the best international lecturers, I managed to bring in experts from ESMO and MASCC to give presentations (they generously waived their honoraria). MASCC and International Association for Hospice and Palliative care (IAHPC) gave me valuable support.

Creating Palliative Care Policy

When the Ministry of Health started developing clinical practice guidelines in Serbia, they invited me to join the team that drafted the first palliative care guidelines with recommendations for the assessment and management of pain, chronic nausea and dyspnea (2004). In 2008, I was appointed as the President of a National Commission for Palliative Care which formulated a National Palliative Care Strategy, adopted in 2009. In 2010, the Commission accepted the recommendations on how to improve legislation to ensure availability and accessibility of opioids for pain relief and palliative care.

Removing barriers to opioid availability: International pain policy fellowship

In 2006, I was selected for the International Pain Policy Fellowship (IPPF) directed by the Pain and Policy Studies Group (PPSG), home of the WHO collaborating center for pain policy and palliative care. Realizing that my hands were tied without available opioids for patients in pain, I decided to apply for this Fellowship. At the time Serbia was left without oral morphine due to some importation problems. Moreover, Serbian policies were mainly focused on preventing abuse and dependence, rather than ensuring access to opioids for medical use. The Fellowship put me in a position to collaborate with the Government and negotiate with drug regulators. My goal was to bring morphine back in the country and change overly restrictive policies. When I mentioned to my friends what I was supposed to do, one of them made a comment that I needed a psychotherapist!

And he was right to a point, as this was my first leadership project but I had limited leadership skills.

I soon realized that my professional expertise, passion and determination are not sufficient to remove barriers. With no training in negotiation, I lacked specific skills to negotiate with drug regulators whose only experience was to *restrict* opioids. Most of all I needed to learn how to listen and understand first -- and then try to be understood.

It was critically important to remove misconceptions and misinformation about opioids and change negative attitudes. We needed to educate healthcare professionals, but also patients/families and the general public, about the indispensability and safety of morphine for cancer pain treatment and palliative care. Although I was supposed to be an advocate, I had no public speaking skills.

I began to think about the value of presentation skills and educational tools, such as textbooks, brochures and effective posters. A designer friend (Mr Nenad Baćanović) gave us a hand with the creative design of our educational materials. A famous journalist, brother of our patient, helped me prepare newspaper articles, and was my media coach for radio announcements and

TV shows. Reflecting on our educational efforts, I realized that although we may be able to transfer knowledge, changing behavior was a different matter.

Serendipity

I met Professor Jacek Luczak at a bus stop during the congress in Vienna. He invited me to the cancer pain management workshop held by Drs Eduardo Bruera and Russell Portenoy.

During his lecture, Dr. Bruera mentioned he was planning to conduct a study to compare morphine and methadone. My immediate thought was, "I have to be a part of it!" Later, I managed to find a moment when Dr. Bruera was alone and I offered to collaborate with him in that research.

I had clinical experience and eligible patients -- and I had already published a research paper on methadone use in cancer pain. As a result, Dr. Bruera invited me to come to Houston! I always had an interest in clinical trials in palliative care as a way to improve management of symptoms. The collaboration with Dr. Bruera enabled me to work within an experienced research team, to design, perform and publish two randomized double blind studies in palliative care: on methadone and chronic nausea.

Later, Prof. Luczak invited me to participate in his courses in Poland, where I received my first formal palliative care education. People I met at his courses were of enormous importance for my work -- Mary Callaway, for example. I also met Professor David Clark, who invited me to visit his team in Sheffield, which became my first international fellowship. During that visit, Professor Clark introduced me to Dame Cicely Saunders.

My teachers

Throughout my career, I have been privileged to learn from the best. They inspired me and helped me to grow. Professor Dušan Beleslin supported my interest in pharmacology and mentored me during my MSc and PhD degrees. My first boss Dr. Siniša Radulovic modeled the way for me as a clinical pharmacologist at the IORS. He believed in me from the start; he gave me a chance and enabled me to act. Many leading palliative and supportive care experts helped me to improve my knowledge and skills. It is impossible to name them all, but to mention a few in alphabetical order, the list of doctors, professors and palliative care experts includes: Sam Ahmedzai, Eduardo Bruera, Mary Callaway, Ron Cameron-Lewis, Frank Ferris, Kathy Foley, Jørn Herrstedt, David Joranson, Holly Yang, Jean Mischel Lasaugniere, Jacek Łuczak, and Fausto Roila. Additionally, Mr. Djordje Vlajić was my first media coach. Ms Duška Jovanović and Ms Ivana Timotijević taught me how to get to know myself better and be a happier person.

In particular, I have to mention Mary Callaway who was like my guardian angel during the development of my career. Similarly, Jamie Von Roenn was my first real mentor. With her

smile, wisdom and warm heart, Jamie helped me become an effective leader. I am grateful and proud to have learned leadership skills from her.

My Hopes and Dreams for the Field of Palliative Care

Palliative care should be embedded in oncology and viewed as a part of standard oncology care. Working together with oncologists, a palliative care team can help to improve symptom control, communication and decision making. It can ease feelings of hopelessness in the face of progressive disease. When further cancer treatment is no longer possible, I often hear families in distress say comments like, “I can’t believe you don’t want to treat him!” or, “Why are you giving up? Aren’t you going to fight for the patient’s life?”

We have to be honest and explain what *care*, *treatment*, and *fighting* really mean in each individual case. When we cannot stop the progression of cancer, we continue to “fight” by not allowing cancer to create suffering. It is a fight for patients’ dignity and comfort. Victory over agony is also a form of victory over disease.

It is about time we accepted that palliative care is a treatment. Actually for some patients palliative care is the only -- and the best possible -- treatment! Too often palliative care is seen as a less-worthwhile approach --almost like 'non-treatment' or abandonment. I remember a patient with an inoperable and incurable abdominal cancer. We relieved his pain, enabled bowel movements, and stopped nausea and vomiting. However, when we told him he could not receive any anticancer treatment, he said, “I have been here for one week and you have done *nothing* for me!”

We hear, “I have to treat patients, they have *nothing* to lose. I cannot *just* leave them to palliative care”. Quality of life is the first priority for patients with very advanced disease. It can be severely ruined with medically inappropriate “treatment”. Therefore, these vulnerable patients have a lot to lose.

Palliative care is not just soothing or comforting patients. Palliative care physicians diagnose and treat their patients, as with any other medical discipline. Moreover, palliative care has well-proven results: improved symptom control, quality of life, satisfaction with care and even prolonged survival.

Finally, advanced cancer patients are now treated longer due to novel developments of cancer therapeutics. Modern palliative care should incorporate knowledge about prevention and management of adverse effects induced by cancer treatments.

Personal message to my team

I am not on my own anymore. I have a team of young, dedicated and enthusiastic people, willing to move our discipline forward and improve our service. It is my pleasure to be their mentor.

Inevitably, we are attracted by innovation and new anticancer treatments. But the progress in oncology should also be judged by the way we are able to support the most vulnerable people -- those with high symptom burden, severe treatment-related toxicities, or incurable. Bryan Stevenson said, "It's that mind-heart connection that I believe compels us to not just be attentive to all the bright and dazzling things but also the dark and difficult things."

Palliative care helps oncologists face the limitations of oncology itself. It teaches that care is always possible although the cure itself is not. It reminds us that the basic purpose of medicine is, "Not only to cure when possible, but also to relieve symptoms and to comfort the patient as much as possible." (Dr. MR Rajagopal, India). The shift from *cure always* to *always care* (and *cure when appropriate*) is, in my opinion, the most important shift to happen in oncology.

Palliative care is about compassion, human fragility and dignity. In that sense, palliative medicine may be one of the noblest disciplines in medicine. It shows us how to become a better physician as well as a better person. This opportunity for constant learning and personal growth is the best legacy of palliative care.

"The good doctor treats the disease, the great doctor treats the patient with the disease."

William Osler, founder of Johns Hopkins Medical School

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