REFLECTIONS ON AN INTERNATIONAL EXPERIENCE

Palliative care in India: Visiting as a volunteer

by Zahra Lalani

What did you learn during your volunteer visits to India?

What we view in the Western world as a right is not a right for all people in this world of ours. In India, the most distressing statistic for me was that more than 75% of all people diagnosed with cancer are in the late stages of the disease at the time of diagnosis, and desperately need pain medicines and palliative care. However, less than 0.5% of people actually receive it. According to the WHO, morphine consumption per capita is regarded as an indicator of pain relief.

In my several visits to volunteer in India, I asked the question that everyone is also wondering about, “Why?” Why do people not have adequate pain medication and palliative care? Well, the answer is not simple. There are a multitude of factors that contribute to the barriers to this right to basic care. Some of these barriers include, but are not limited to: beliefs about cancer being contagious in some villages, poor access to screening programs and diagnostic tools, limited knowledge about signs of cancer, religious beliefs related to suffering, a pervasive stigma surrounding a cancer diagnosis, overarching societal fears around addiction, and bureaucratic barriers to obtaining licences to prescribe opioids for medical use, as well as lack of palliative care education in medical schools. In the recent years, there has been a movement by the government of India and some organizations to change the landscape; the future looks promising.

What frustrated me the most is that the cost of morphine is affordable. The poppy is legally cultivated in India and opium is extracted and exported to the rest of the world for morphine production and use. However, it is not readily accessible to people of India. This is a violation of basic human rights and results in immense and immeasurable suffering that I found palpable and overwhelming.

What were you concerned about while you were there?

There were several observations that I found concerning and emphasize the different culture and ways of handling health care.

On my first day at the MNJ Institute of Oncology in Hyderabad, India, masses of people were lined up to see the doctor and a woman was screaming in agony—I wondered, was the woman screaming because she was in labour? For me, that was the only other time I heard that desperate scream.

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It was from a woman who was on the floor screaming in agony because a cancer had ravaged her body to destruction. Yet, the cancer she had is curable in most countries. What I have learned subsequently is that most women die of this cancer due to lack of screening programs for early detection.

There seemed to be an acceptance for human suffering. People with large tumours were walking about with distorted body parts. It felt to me something like a movie set must feel, perhaps a production special effects team had come and put this grossly large tumour on a human being who then had to walk around with it.

Wounds were not only exposed without adequate dressings, some had maggots that had to be extracted. The maggots did not phase the team there; it was part of the clinical “expertise” required to work in the pain and palliative care outpatient unit.

An oncology nurse for the last 14 years, this was the first time I witnessed these types of scenes. I felt like cancer was literally in my face and I could not deny it even if I wanted to. It was surreal; and people walked about seemingly resigned to their fate. It felt like there was no urgency and neither was there an expectation that anyone should react in any way to mitigate the suffering. On reflection, over the days, I felt helpless and sad to say that I, too, as a coping mechanism, normalized this scene.

The small percentage of people who received palliative care were so thankful and appreciative, they felt “lucky” to have received the care that most of us would deem as a right.

**How did you handle your concerns? What would you like other Canadian nurses to know about the environment and the setting where you were?**

I felt like I was in another world. And I was so grateful that in my world we had a different reality. I also felt a sense of guilt for having access to health care and, in particular, access to palliative care, if I ever needed.

I continue to volunteer with Two Worlds Cancer Collaboration Foundation, a Canadian not-for-profit charity that is working to change the disparity of our two worlds.

I decided that, while getting to escape back to my world was an option, I could not forget the people who desperately need access to basic care. As a result, I have engaged in many initiatives to help raise awareness of this disparity and helped raise funds with my colleagues, friends, and family to grow the palliative care program in India.

My first attempt to raise awareness was with a group of about 10 close family and friends and the support was overwhelming! I was able to get donations without even asking for them. This led me to go to churches, temples, and Rotary Clubs. When I do this, I feel I am sharing the stories of the people who have no voice.

I have been overwhelmed by the support from so many people; people I hardly know have stepped up to support this initiative. It has been a demonstration of human compassion that I would never have expected! This has ultimately resulted in fundraising initiatives in Canada to continue to support this work. We have had approximately 400 people in attendance at our dance fundraiser in 2015 and, prior to that in 2014, a gala was put on and raised thousands of dollars in donations towards this cause. We hope to continue to have these events at least every two years and have started planning for one in 2017.

During my experiences in India, I felt deeply wounded by what I observed. But through the outpouring of support by Canadian friends and family, I have found a way to change this experience into something positive.

Thank you to all the people who patiently listened to the stories and who have stepped up to help this initiative.