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My Life Inspired by Love and Guided by Knowledge

When I started Palliative Care in Mongolia, I was already a pediatrician, a consultant doctor with the pulmonary department of the Mother and Child Health Center of Mongolia and a teacher of pediatrics in the Medical University of Mongolia with 20 years' experience. The General Practice Department of the Medical University was established in 1998, and I was obliged to head the newly-established General Practice Department there.

These were among the blackest days of my life because I didn't like this obligation. Furthermore, I needed to learn many new disciplines, like geriatrics, gerontology, psychosomatic medicine, family medicine and Palliative Care. At that time, none of these disciplines yet existed in Mongolia or within the Mongolian Health Care System.

I had the occasion to participate in the Palliative Care Conference organized by the European Palliative Care Association in 2000 in Stockholm, with the support of the Open Society Institute. This conference really opened my eyes because I had never before heard about Palliative Care, pain management, symptom management, or the psychosocial support of terminally ill patients. OSI opened our eyes to a very humanistic and very important part of medicine, which was not available in post-socialist countries.

I understood for the first time that incurable patients can still be treated, and the treatment name is Palliative Care. It is a human right to receive palliative treatment even when the disease is not curable. I learned about pain management and symptom management for incurable patients that improved their quality of life.

In the medical schools of Mongolia, Russia never told us about improving quality of life. I saw how schoolchildren in Stockholm learned something about Palliative Care and an education program on Palliative Care was included in the middle school program -- at a time when nobody in Mongolia knew anything about this kind of medicine.

When I returned home after the Conference in Stockholm, I visited the Minister of Health for Mongolia and asked about existing Palliative Care services in our country. The Minister of Health did not understand my question, because even the terminology "Palliative Care" did not exist in our Mongolian language, let alone any Palliative Care service anywhere in the country.

My ambitions drew me to establish Palliative Medicine in Mongolia, but I didn't know the needs of Palliative Care in Mongolia and my knowledge of Palliative Medicine was very poor. For this reason I decided to conduct a small survey with two of my student-family residents. Through family doctors, I received the home addresses of patients with "poor prognosis" (the doctors did not understand the term "Palliative Care patients".) Then one Sunday we visited them. We talked with them about their problems and recorded all the discussions. Each of these people touched me and my students. I watched the recorded interviews that evening and the next day -- again and again. I cried alone watching these interviews.

I could not forget the young woman, who was 28 years old and the mother of two beautiful girls. She had stomach cancer and cried because of severe abdominal pain. She needed to participate in three medical commission meetings to receive just 10 tablets of Morphine, which helped her for barely two days before the prescription was finished. The district Oncologist had no authority to prescribe more opioids. The woman cried and asked her father to kill her because her pain was too severe. She could not bring herself past her pain to think about her small girls. She just wanted to stop suffering by dying. Her parents cried and did nothing for her. She only received first line analgesics which did nothing to mitigate her pain. The District Hospital did not admit her because they had no beds for cancer patients. (Every year, the Ministry of Health for Mongolia decided the number of hospital beds available for a restricted number of diseases.) The National Cancer Center did not hospitalize her because her cancer was in stage IV -- the incurable stage. We had no Palliative Care department yet.

I also remember a 56-year-old man with lung tuberculosis who lived in Poor Street, where people live in gers. In this instance, seven people lived in one ger: the patient, his wife, two sons, one daughter-in-law, and two small grandchildren, one aged two years and the other just six months. The patient had severe chest pain, fever, cough, dyspnea, cachexia, and sputum with blood. He received free medicine for treatment of his tuberculosis, but he could not tolerate this medicine because of multiple side effects. All family members were at risk of infection from his TB. It was difficult to see two small children staying with their grandfather, who was coughing and spitting out sputum with TB bacteria and blood. He was not hospitalized in the TB department of the National Center for Infectious Diseases. In fact, the TB doctors ignored him because he could not

tolerate medicine. One physician in the TB department wrote an unapproved diagnosis of “Lung Cancer”. The National Cancer Center did not hospitalize him because his diagnosis of “Lung Cancer” was not approved -- and he had tuberculosis. He died at home without any medical help.

The new knowledge and attitude I learned at the Stockholm Conference was crucial in my life. Memories of a small girl came back to me. I was on night shift at the Mother and Child Health Center. A ten-year-old girl with leukemia was in the hematology department there. She had severe bone pain throughout her entire body; she could not move, sleep and never smiled. Her face reflected severe suffering. Her parents sat all night on a stool near her bed and massaged her legs and hands. Every time they massaged one body part, she would grimace with pain from another part of the body. So they would massage the newly-painful area to try to ease her pain. She was never out of pain. They stayed up all night with her and they themselves were unable to sleep, either. She suffered from severe pain until her death, and only received a first-line analgesic.

At that time, some 96% of Mongolian children with leukemia suffered from pain and died in the hematology department because of poor chemotherapy and the absence of pain management. The Mother and Child Health Center of Mongolia had just first-line analgesic, not even second-line analgesic and morphine. Medical workers feared opioids and thought that morphine would kill patients.

Memories came back to me of my father who died of lung cancer, and my mother-in-law who died of liver cancer. When my father died, I was just 17 years old and a first-year student at the Pediatrics Institute in Leningrad, Russia. I did not have the opportunity to care for my father, or to say goodbye. When I returned to Mongolia, my sister told me that our father suffered from pain, dyspnea and cough. As a professor at the University, he was hospitalized in the best hospital in Mongolia. But the hospital had just first-line analgesics which did nothing to ease his suffering.

My mother-in-law died from liver cancer when I was 26. She lived in our apartment with my family for the last two months of her life. I cared for her. I fed, washed, and changed her, but I could not palliate her pain and suffering because I didn't know how to treat the pain. She received just first-line analgesics which did nothing for her.

During these home visits and discussions with patients and families, I realized that eventually every family will need Palliative Care someday for their loved ones. These one-day home visits were enough for me to make the hard decision to establish Palliative Care in Mongolia, because I saw so much suffering in these families -- physical, psychological, social, and financial. I understood that establishing comprehensive Palliative Care could ease their suffering. A combination of the patients' suffering, my ambition, and my personal life tragedies prompted me to make this choice.

But I had limited knowledge of Palliative Care myself. My English was very poor. Nothing on Palliative Care existed in Mongolian and Russian books. It would be a big challenge for me to establish Palliative Care from zero with people in a poor-resource country like Mongolia. We had no awareness about Palliative Care, patients' right, or quality-of-life issues. The terminology "Palliative Care" and "quality of life" were new for Mongolian healthcare policy-makers and health workers.

One healthcare policy-maker in the Mongolian Ministry of Health asked me, "Why do you want to establish Palliative Care for dying patients when we do have not enough money for living patients?" When I mentioned "patients' quality-of-life", the officer with the Ministry of Health confused it with "quality of health services". No "patients'-rights law" exists in Mongolia even today. The general population, medical workers, and healthcare policy-makers did not accept using morphine for pain management. They were fearful of morphine and they had misconceptions about morphine use. Some of them thought that morphine would kill the patient, and others thought that use of morphine would increase opioid abuse in Mongolia. It was a challenge to start up a new type of medicine in Mongolia, especially for me. After all, I had invested 20 years becoming an experienced pediatrician.

But the Open Society Institute (OSI) allowed me to participate in basic and advanced courses on Palliative Care in Poznan, Poland (2001, 2002), then at the Leadership Conference in Budapest (2002), and at the Policy Development Conference in Istanbul (2004). I translated and published several WHO guides on pain and symptom management from English into Mongolian. The knowledge gained from Palliative Care courses and WHO guides gave me the strength, faith and wings to fight for establishing a Palliative Care system in Mongolia with policy, education, drugs and services.

OSI supported my project for organizing a Leadership Conference on Palliative Care in 2002. Participants at this Conference included parliamentary members, Presidential consultant N. Lkhagva, the Vice-Minister of Health N. Udval, WHO consultant Jan Stjernswärd, officers of the MoH, health directors from 21 provinces in Mongolia, health directors of nine districts of Ulaanbaatar, directors of all medical schools of Mongolia, media, and members of the Mongolian Palliative Care Society.

At the Conference, we introduced newly-translated-and-published WHO guides on pain management, symptom management, and pediatric Palliative Care. This gave me the hope that healthcare policy-makers would accept Palliative Medicine to be an essential part of healthcare.

We also introduced another translated WHO guide, "Achieving balance in opioid availability" and UN's book, "Availability of opioids for medical use". I wanted health policy-makers to accept the use of morphine for pain management and lose their "morphine phobia".

I translated and introduced the Catalanian experience, which established that Palliative Care saves money in the healthcare budget. I hoped that our healthcare budget experts would not worry about the cost of implementing this new health service in Mongolia.

The 2002 Leadership Conference on Palliative Care in Ulaanbaatar was successful. I delivered a presentation from my heart, using patients' stories and WHO, UN guides and books, and the Catalanian experience. WHO consultant Jan Stjernswärd made strong recommendations to healthcare policy-makers using the WHO triangle. Participants at the Conference received all WHO, UN books, and a copy of the Catalanian experience in Mongolian. They also received a calendar with photos of an old woman, cared for by her son, and the words, "Life begins with love and should end with love."

For the first time, I felt that the atmosphere of this Conference touched participants' hearts. Participants started to understand the need for Palliative Care, the importance of morphine in pain management, patients' rights which had been long-ignored, and the WHO triangle.

By the end of the Conference, all participants realized the importance of Palliative Care and made a commitment to initiate it in Mongolia. As result of my efforts, I established the Mongolian Palliative Care Society (MPCS) in 2000 and began activities to develop Palliative Care. With the support of OSI and Help-to-Hospices, Mongolian Palliative Care Society organized:

1. The first Palliative Care basic courses for medical workers in 2002 and 2003
2. Advanced courses for national trainers on Palliative Care in 2005, 2006, and ongoing postgraduate courses and specialization courses on Palliative Care since 2004 until today. I educated more than 3,000 medical workers in short-term courses (several hours and five-day courses) and 260 medical workers by specialized courses (three-to-six months)
3. Leadership development conferences for healthcare policy-makers in the Ministry of Health and directors of medical schools in 2002
4. Palliative Care Policy Development Conferences in 2005 and 2006
5. Workshops for essential drugs for Palliative Care in 2003, 2004, 2005, and 2012
6. Translated, published and distributed core WHO guides on Palliative Care for doctors, medical schools, and participants at all of the above-mentioned conferences. We provided advocacy and advertisements on Palliative Care for healthcare policy-makers, healthcare workers, patients, caregivers and the general population via TV, radio, leaflets, and calendars since 2000 continuing to this day

Now we have Palliative Care included in Health Law, Social Welfare Law, National Cancer Control Program, approved Palliative Care Standard, and Pain management guide. Affordable morphine has been available in Mongolia since 2006. Consumption of morphine has increased annually and is prescribed by Palliative Care doctors, oncologists and family physicians. They now can prescribe

appropriate doses of opioids every seven days until death (whereas before only oncologists had the right to prescribe a maximum of ten tablets of morphine).

Since 2005 all medical schools in Mongolia have Palliative Care education programs, and social workers have Palliative Care education programs. Palliative Care services disseminate information throughout Mongolia via the Palliative Care department in the NCC, Green Home Hospice, Grace Hospice, Hope Hospice, Ach Hospices. Nine districts and 21 provincial hospitals have the right to hospitalize Palliative Care patients.

I graduated in 2010 from the Palliative Care Fellowship Program at San Diego Hospice and in 2014 the Leadership Development Initiative (LDI) program at Ohio Health Research Institute. LDI has helped me improve myself as a leader. During the last two years, I graduated from an English course at the Leadership Institute, and a Project Management class at the Mongolian Academy of Governance. I feel like I am a leader of Palliative Care in Mongolia and now I am more confident and happier.

I think I have been able to share my vision, make change, and implement Palliative Care using successful materials (WHO guides, UN book, the Catalanian experience) with appropriate people (Mongolian healthcare policy-makers) within a suitable timeframe (2000-2010).

I am happy now, because the WHO triangle on Palliative Care is implemented in Mongolia. Fifteen years ago, I didn't enjoy being the head of the GP Department and the prospect of learning new medicine. Now I am grateful that I had this opportunity to change my life because I feel my life has been used appropriately. I have satisfaction from my job and from my life -- even if it has been very busy and I have no time for vacations.

"My heart, my brain, like the stomach, want a varied diet." (Gustave Flaubert). Learning Palliative Care, doing Palliative Care I feed my heart and brain. *Jean Paul Richter* said, "Only actions give life strength; only moderation gives it a charm." My work in establishing Palliative Care strengthens my life and makes it meaningful. Leonardo da Vinci said, "As a well-spent day brings happy sleep, so life well-used brings *happy death*." I believe that my life has been used well.

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