

Honorable chairman, colleagues and guests!

On behalf of the International Association for Hospice and Palliative Care Association (IAHPC), Vienna NGO Committee on Drugs, and the International Renaissance Foundation, Ukraine let me thank the Commission on Narcotic Drugs (CND) and United Nations Office on Drugs and Crime (UNODC) for the opportunity to speak regarding role of the civil society organizations in ensuring increased access to controlled medications and for pain management and palliative care in particular. I am a physician trained in palliative care, and while currently I'm not involved in clinical work I want to share with you some real life stories that are the reason and inspiration for the work my colleagues and I are doing.

You may wonder why I'm so afraid of calls on late Friday afternoons! I get those quite often, but this time I was expecting it from my old colleague who was asking if I could put her in touch with a doctor who would prescribe morphine or another strong opioid to control pain of her father dying from terminal cancer. I wasn't surprised because we already were talking about his condition and I suggested that they discuss pain management options with their family doctor and plan how they would get it in case of an emergency. She was postponing this conversation and now she was desperately looking for a provider who could issue a special prescription form, since their family doctor was not available on the Friday afternoon and there was no mechanism in place to ensure access to morphine. The chief doctor of the facility was not willing to take responsibility and issue the needed prescription. This was not during medieval or Soviet time – this was February 2017 in Kyiv, capital city. It took my colleague, a renowned women's rights activist, to finally get a prescription the following Monday, and provide pain management 6 hours before her father actually died.

Civil society organizations together with public health specialists and human rights activists played essential role in catalyzing work towards balanced drug policy and continue to drive this process in the Eurasia region, namely in such countries as Armenia, Georgia, Moldova, Kyrgyzstan, Tajikistan and Ukraine, by forming a broad regional coalition. Most of the progressive developments I will describe are reflective of the countries listed above while I would like to focus on Ukraine – our successes and challenges. Humanistic and human rights approach was made the center-piece of the advocacy to change national legislation to reduce excessive barriers in access to pain management. Systemic work during 2011-2013 on the national level allowed significant positive shifts enabling patients to receive prescription from family doctors, and not from a limited number of specialists only; prescription validity was extended from 3 days to 10 and prescribed amounts increased from 3 days to 15 days worth of supply to minimize treatment interruption. Geographical restriction was substituted with the right to fill in the prescription at any pharmacy licensed to operate with controlled medications compared to only ONE pharmacy that had contract with the health facility issuing the prescription.

Progressive legislative changes and continued information, awareness raising and advocacy campaigns led by patients' relatives and providers, facilitated registration of oral morphine immediate release in Jan. 2013. Lifting the maximum dose of 50 mg of morphine per day to at least 200 and adding provision on individual dose titration was final step in dismantling the old system. With over 5000 health providers trained across the country, some of them participating in trainings and exchanges on the regional and international level stimulated faster providers' practice changes.

In 2016 report carried out by human rights organizations documented that only 15 to 20% of all patients receive adequate pain management and have uninterrupted access to medicines. Although still unacceptably low, it is a significant win compared to the data from 2010 report conducted by Human Rights Watch and same NGOs that documented access to controlled medications and palliative care at the level of under 10% of the need.

Patients needing adequate pain relief in our region continue to suffer, although Ukraine has one of the most liberal regulations on controlled medicines' use in the Eastern Europe. We can't afford to retreat in the shadow of the opioid overdose crises in USA, which was fueled by deceptive information campaigns by pharmaceutical company. This has spread even more myths and mis-information about the psychological and physical outcomes of opioid use. Now we are observing a concerning new stage of the war on pain-control medications. Strong evidence exists that punitive, supply control approaches are not effective, while leaving patients bedridden and crippling in pain or being pushed to turn to black market, use home-extracted remedies, or suicide.

Instead of supporting restrictive measures only, we should strengthen the role of expert civil society organizations and human rights advocates. To improve quality and continuity of credible and consistent information about medical use of opioids, it is vital to increase the role of pharmacists and engage them more in work with patients and policy makers, to counteract the negative influence of the pharmaceutical industry. Of course we understand that the pharmaceutical companies supply the essential medicines, so are an important stakeholder. They should bear full responsibility for presenting complete, truthful, evidence-based and comprehensive information regarding their products.

The palliative care community in Ukraine, as well as throughout the region, is concerned that this new war on controlled medicines for pain management is creating a backlash for progressive legislation and practices achieved through years of intensive, meticulous work with stakeholders, drug control agencies, health and social workers, pharmacists. We have achieved the level of trust and understanding in the society to talk about pain management and opioids without the denial or fear of being prosecuted. We need to preserve this communication and participation in decision making of patients and families, nor return to the dark times of pleas for pain control or screaming neighbors in the apartment next door.

Human rights activists, families and palliative care groups have achieved many successes in recent years, yet we still have a long way to go. My mother was able to live in dignity and relatively happily for her final 8 months on controlled medications, despite the terminal cancer, because I had the knowledge, instruments and certain influence. The leftover medicines after she had passed were properly utilized contributing nothing to misuse or diversion. I call on honored colleagues from Commission on Narcotic Drugs, official delegations and policy makers – to please include human rights activists and public health experts on your delegations and task forces to continue with the balanced drug policy strategy and implementation, and not slide into restriction and denial, causing more harm.

Thank you for your attention!