

## **Presentation by Amanda McRae**

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### **What is palliative care?**

- WHO – comprehensive set of health services aimed at improving the quality of life of people with incurable illness and their families, including physical, psychological, and spiritual care.
- Unlike curative healthcare, its purpose is not to cure a patient or extend his or her life.
- Key Objective: Relief from pain

### **How does this issue affect older persons?**

- Older persons are particularly in need of palliative care services.
- They are more likely to have chronic and end-of-life diseases, such as cancer, diabetes, heart failure, and dementia, that entail pain and require palliative care treatments.
- Approx. 80 percent of the world's population has either no, or insufficient, access to treatment for moderate to severe pain.
- Tens of millions of people around the world— including around 5.5 million cancer patients and 1 million end-stage HIV/AIDS patients—suffer from moderate to severe pain each year without treatment.

- HIV/AIDS
  - Chronic pain is common symptom
  - Growing bigger due to anti-retrovirals treatment
  - Simultaneous delivery of palliative care and ART improves treatment adherence.
- Cancer
  - 60 to 90 percent of patients with advanced cancer experience moderate to severe pain.
  - The World Health Organization says that "[m]ost, if not all, pain due to cancer could be relieved if we implemented existing medical knowledge and treatments."
- How to treat?
  - Basic oral morphine is inexpensive and can be administered by patients or family members in the same fashion as any oral medicine.
  - Medicines to treat pain are often cheap and effective
  - Morphine – produced in large quantities, comes in oral and shot form
  - Morphine and codeine (a mild opiate) both on WHO essential medicine list

## A human right to palliative care

- Right to Highest Attainable Standard of Health
  - ESCR and CRPD
  - Accessing palliative care is part of the right to health.
  - Indeed, the UN Committee on Economic, Social and Cultural Rights has called for “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.
  - Progressive realization – depends on resources
  - But the UN Committee on Economic, Social, and Cultural Rights has said that there are core obligations that all states must adhere to, regardless of resources.
  - These core obligations include
    - providing essential medicines, as defined by the WHO. These include morphine and codeine (a weak opioid).
    - Ensuring equitable distribution of all health facilities, goods, and services; and
    - Adopting and implementing a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population

- Framework
  - No Interference with palliative care
    - The CESCR “refrain from interfering directly or indirectly with the enjoyment of the right to health.”
    - States may not deny or limit equal access for all persons, enforce discriminatory health policies, arbitrarily impede existing health services, or limit access to information about health.
    - Drug control regulations - states should ensure that their drug control regulations do not unnecessarily, and therefore arbitrarily, impede the availability and accessibility of essential palliative care medications such as morphine.
    - A balance must be struck between preventing misuse and ensuring accessibility and availability of medicines for licit health purposes.
  - Facilitating Development of Palliative Care
  - Ensuring Integration of Palliative Care into Health Services
    - The right to health requires that states take the steps necessary for the “creation of conditions which would assure to all medical service and medical attention in the event of sickness.”

- The Committee on Economic, Social and Cultural Rights has held that people are entitled to a “system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.”
- In other words, health services should be available for all health conditions, including chronic or terminal illness, on an equitable basis.
- The committee has called for an integrated approach to the provision of different types of health services that includes elements of “preventive, curative and rehabilitative health treatment.”

### **Cruel, Inhuman, or Degrading Treatment (CIDT)**

- Apart from prohibiting the use of torture and other cruel, inhuman, or degrading treatment or punishment, the right also creates a positive obligation for states to protect persons in their jurisdiction from such treatment.
- As part of this positive obligation, states have to take steps to protect people from unnecessary pain related to a health condition.
- Manfred Nowak, the former UN SR on T and CIDT or P wrote in a joint letter with UN Special Rapporteur on the Right to Health Anand Grover in December 2008,
  - Governments also have an obligation to take measures to protect people under their jurisdiction from inhuman and degrading treatment. Failure of governments to

take reasonable measures to ensure accessibility of pain treatment, which leaves millions of people to suffer needlessly from severe and often prolonged pain, raises questions whether they have adequately discharged this obligation[\[172\]](#)

- In a report to the Human Rights Council, Nowak later specified that, in his expert opinion, “the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment.”

### **Examples from the field**

- Two common themes
  - Restrictive drug regulations
    - International law requires states to make narcotic drugs available for the treatment of pain while preventing abuse.
    - But that the strong international focus on preventing abuse of such drugs has led many countries to neglect that obligation.
    - The 1961 Convention on Narcotic Drugs states that these drugs are "indispensable" for the relief of pain and suffering.
    - Although UN drug treaties envisaged a balance between preventing abuse and making sure narcotic drugs are available for medical purposes.

- In practice, many governments have implemented strict laws and policies that target drug abuse and ignored their obligation to ensure legitimate access to pain relief medicines.
- Training of health care workers to provide palliative care – not part of medical school curricula; not integrated into health services provisions.

- India

- Fewer than 4 percent of patients with advanced cancer had access to appropriate pain treatment, Based on official morphine consumption reports
- Increased government funding for cancer has not emphasized palliative care.
- Cancer - Many major cancer hospitals in India do not provide patients with morphine, despite the fact that more than 70 percent of their patients are incurable and likely to require pain treatment and palliative care.
- HIV - Health centers offering services to people living with HIV similarly do not have morphine or doctors trained to prescribe it.
- Restrictive drug regulations.
  1. Many Indian states have excessively strict narcotics regulations that make it very difficult for hospitals and pharmacies to get morphine.

2. In 1998, the central government recommended that states adopt modified regulations, but more than half of India's states had not done so.
- The failure to train doctors.
    1. Most medical students and young doctors receive no training on pain treatment and palliative care because the government does not include such instruction in relevant curricula.
    2. As a result, most doctors in India simply do not know how to assess or treat severe pain.
  - Poor integration of palliative care into health services.
    1. National cancer and AIDS control programs do not contain meaningful palliative care components, thus depriving such care of public funds and relegating it to second-tier status.

#### - Ukraine

- At least 80,000 cancer patients in Ukraine experience severe pain every year, cancer mortality figures suggest.
- In addition, many other patients, including those with HIV, Tuberculosis, or other infections or illnesses, may face acute or chronic severe pain.
- Drug regulations. In its efforts to crack down on illicit drug use, Ukraine has adopted some of the most restrictive drug regulations in the world, without appropriate regard to the need for access to drugs on medical grounds. These

regulations severely interfere with the medical availability of medications like morphine.

- The lack of oral morphine. For decades, oral morphine has been the cornerstone of cancer pain treatment. The World Health Organization considers it an essential medicine. Yet, Ukraine's government has failed to make the medication available through the public health care system. It is not available in private clinics either. Only two other European countries - Armenia and Azerbaijan - do not stock oral morphine.
- Ukraine's drug regulations require injectable morphine - the only formulation of the medication available in the country - to be administered by a health care worker directly to the patient. Since morphine acts for just four to six hours, this means that a health care worker must visit a patient who is dying at home, as most cancer patients in Ukraine do, six times a day. Human Rights Watch research shows that most patients get either no morphine or one or two doses a day. If oral morphine were available, patients could receive a take-home supply and take the medications themselves.
- Training of health care workers. Medical students and young doctors do not receive adequate training in modern pain treatment approaches.

## **Recommendations**

Legally binding standard for right to palliative care