

# PALLIATIVE CARE AND ACCESS TO MEDICATIONS FOR PAIN TREATMENT

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The World Health Organization (WHO) recommends that controlled, essential medications are absolutely necessary for treatment for moderate to severe pain for people with cancer<sup>1</sup>. Yet millions of people worldwide with life-limiting conditions are living and dying in pain and distress due to the lack of availability and accessibility of these medications. WHO estimates that 5.5 million people with cancer suffer from moderate to severe pain<sup>2</sup>. The disparity in the availability and consumption of treatment for pain is stark with an estimated 80% of the world's population living in countries with low or no access to pain treatment for moderate to severe pain<sup>3</sup>. More than 99% of untreated deaths in pain from cancer and HIV are in low- and middle-income countries<sup>4</sup>. Access to appropriate pain treatment for children is a particularly challenging issue.

Palliative care is a patient-centred approach that improves the quality of life of adults and children living with life-limiting conditions, including cancer. It addresses their physical, psychological, social and economic, legal and spiritual problems from the point of diagnosis throughout the life course<sup>5,6</sup>. Palliative care is not just about the treatment of physical pain but this is a core element of it; and access to the medication needed to treat moderate to severe pain, particularly opioid analgesics, is one of the major practical barriers to delivering quality palliative care worldwide.

Yet while the barriers are numerous, initiatives around the world are seeing an increase in access to palliative care services, including pain treatment. The percentage of countries with at least one palliative care service rose from 49% in 2006<sup>7</sup> to 58% in 2011<sup>8</sup>.

## The barriers

Multiple barriers have been identified which affect the availability and accessibility of pain treatment for people living with life-limiting illnesses. These include:

### *Excessive regulatory policies and restrictions*

The issue of overly excessive regulatory policies and restrictions is one of the major barriers to the availability of access to pain treatment worldwide. The 1961 Single Convention on Narcotic Drugs<sup>9</sup> highlighted the need for the

availability of opioids for medicinal purposes and this has been repeatedly reiterated by the World Health Organization<sup>10</sup> and the International Narcotics Control Board<sup>11</sup> as well as non-governmental organizations. It is clearly acknowledged that the role of governments is to ensure balance in national policies on controlled substances to ensure that people in need of medicinal care, including pain treatment, can access the medications they need, while addressing issues of misuse and diversion<sup>12</sup>.

However, barriers and over-regulatory policies remain. A report published by the European Society for Medical Oncology (ESMO) and the European Association of Palliative Care on regulatory barriers for cancer pain in Europe, clearly highlighted the "poorly-considered regulations and deficiencies in public policy" across Europe, and particularly in Eastern Europe<sup>13</sup>. The regulatory barriers included the need for a permit (or to be registered) to receive opioid prescriptions, the need for a physician to have a special permit, requirements of duplicate or triplicate prescriptions, restrictions in prescription and daily dose limits, limitations on where opioids can be dispensed and inadequate provision for opioid prescribing in emergency situations<sup>14</sup>. All of these policies create barriers that prevent people from accessing the quality clinical care that they need.

These excessive regulations, policies and restrictions are by no means limited to Europe. The African Palliative Care Association has identified supply and legislation as two of the

common hampering factors in the availability of opioids<sup>15</sup>. In Kenya, Human Rights Watch has highlighted the government's lack of action to centrally procure opioid medications<sup>16</sup>. In India the ineffective supply and distribution systems and the excessively strict drug control regulations were reported as a major barrier to opioid availability<sup>17</sup>.

All of these barriers are present around the world to a lesser and greater extent, seriously limiting the accessibility of pain treatment for those who need it.

### **Education and training of health professionals**

The effective use of opioid analgesics for the treatment of pain requires education and training of health professionals. It is well documented that palliative care should be a mandatory component of the curricula for undergraduates and postgraduate medical and nursing students and pharmacists<sup>18</sup>. Yet, unfortunately, in many countries this is simply not the case. Without effective education and training, health professionals may not prescribe out of fear and lack of knowledge about the benefits of the medications. This has resulted in stocks of morphine left to go out of date on hospital and pharmacy shelves, while patients in care remain in pain and distress<sup>19</sup>.

### **Lack of palliative care policies**

At the global level, numerous policies, resolutions and guidelines clearly outline the need for access to medications for pain treatment<sup>20</sup>. The WHO Essential Medicines List<sup>21</sup> includes opioid analgesics<sup>22</sup>. However, at the national level, policy development is challenging. Many countries do not have cancer control policies. Indeed in 2006, only two countries in Africa had a cancer control programme<sup>23</sup>. It is thought that 38 countries worldwide have either a stand-alone national hospice and palliative care policy, or palliative care is integrated within the existing national health, HIV or cancer policy<sup>24</sup>. While many countries have opioids on their essential drugs list, this does not seem to be reflected in the consumption figures of opioid analgesics as reported by the International Narcotics Control Board.

The need for palliative care policies and integration of palliative care into existing HIV, health and cancer policies is fundamental to the development of palliative care services and the availability of analgesics.

### **Fear, myths and misunderstandings**

Fear, myths and misunderstandings around the use of opioid analgesics, including morphine cut across many of the issues which create barriers to its availability. One of the most pressing common fears which has been shown to limit prescribing by

health professionals and attitudes of patients and family members is the fear of dependency and addiction. However, a systematic review of research papers showed that only 0.43% of patients with no previous history of substance abuse treated with opioid analgesics to relieve pain abused their medication and only 0.05% developed dependence syndrome<sup>25</sup>.

In relation to diversion, the experiences of countries such as Romania and Uganda show that in relatively low-resource settings, systems can be put in place that ensure the availability of opioids for medicinal use while minimising diversion. This is fully in line with the WHO and INCB recommendations: a balance needs to be achieved between ensuring that drugs are available for medicinal and scientific purposes, while addressing misuse and diversion.

A common fear of health professionals and family members is that opioid analgesics, including morphine, will hasten death. The primary focus of palliative care and the administration of pain treatment is to improve quality of life and reduce suffering and not to hasten death. Indeed, there is some evidence that palliative care may in fact extend life<sup>26</sup>.

There are considerable misunderstandings around the cost of pain treatment. In Uganda, the cost of 10 days' pain treatment using morphine costs the same as a loaf of bread<sup>27</sup>. Yet, it is clear that in some countries, costs are significantly higher due to high importation taxes on morphine powder<sup>28</sup> or costing structures. There also remains the challenge that more expensive, sustained release morphine is often made available in countries, rather than the more affordable, immediate release morphine, despite this not being to the patients' clinical benefit<sup>29</sup>.

## **National progress**

### **Uganda**

Uganda has led the way in Africa in developing innovative solutions to address some of the logistical and regulatory challenges in ensuring the availability and accessibility of opioid analgesics. Founded in 1993, Hospice Africa Uganda moved forward the vital task-shifting agenda making Uganda the first country in Africa to allow nurses and clinical officers to prescribe morphine for pain treatment<sup>30</sup>.

In 2010, there was an incident when the government stocks of opioids ran out and were not available to treat many people living with life-limiting illness. The UICC's Global Access to Pain Relief Initiative, working with the Hospice Africa Uganda, the African Palliative Care Association and relevant government authorities worked to address this situation by developing an innovative, cost-effective, public-private partnership, whereby the government procures the morphine for local production by Hospice Africa Uganda itself<sup>31</sup>.

## Global change

At the global level, there have been a number of initiatives to influence policy change, programming and public awareness around the issue.

### *Policy and guidelines*

The World Health Organization has republished and reviewed the “Ensuring balance in national policies on controlled substances” which provides clear guidelines to national governments on how to ensure the availability and accessibility of controlled medicines<sup>32</sup>. These guidelines need to be utilized by national governments and acted upon.

The World Health Organization also released guidelines on the pharmacological treatment of persisting pain in children with medical illnesses<sup>33</sup>. The International Children’s Palliative Care Network (ICPCN) have also developed an e-learning training module linked to these guidelines<sup>34</sup>.

In 2012, the Worldwide Palliative Care Alliance, in collaboration with the World Health Organization, published a report on the global mapping of palliative care at the end of life. This gives a comprehensive picture of the need and the availability of palliative care.

### *Raising public awareness*

It has long been recognized that the myths and preconceptions relating to opioids is affecting their availability. There are a number of activities specifically aimed at addressing public perceptions to bring about changes. Two examples of these kinds of activities include:

#### ***World Hospice and Palliative Care Day***

Every year, approximately 70 countries participate in activities around the world to raise awareness and understanding of hospice and palliative care. Managed by the Worldwide Palliative Care Alliance, the day creates an opportunity for highlighting the issues that affect us<sup>35</sup>.

#### ***Life before Death***

For the past year, the Life Before Death series has generated short films and a documentary film across 11 countries highlighting the remarkable health professionals battling the sweeping epidemic of pain. It highlights the experience of palliative care and access to pain treatment from the perspective of patients, family members, health professionals and advocates<sup>36</sup>.

#### ***Engaging champions***

The Open Society Institute has funded a leadership programme to build the leadership of national palliative care

professionals in collaboration with the San Diego Hospice and Institute for Palliative Medicine.

From 2006, the Pain and Policies Studies Group at the University of Wisconsin have run a fellowship to support national hospice and palliative care champions to change policy and practice around the availability of pain medications around the world.

The Global Access to Pain Relief Initiative is building champions within governments to support access to pain treatment, beginning with Kenya.

## Palliative care in emerging health systems

The importance of palliative care as a fundamental part of health and community systems is well argued. As policies and programmes are developed, the following key issues need to be taken into consideration:

### *Caring for an ageing population*

The need for palliative care continues to grow as the population ages and there is an increased incidence of non-communicable conditions. More needs to be done to promote and ensure dignity and quality of care for older people, throughout the life course to the end of life. This should include emerging health systems and should ensure that the complex and specific care needs of an ageing population are being met.

Models of care that look at the training and mentorship of older people’s peer support groups, linking community carers with health and social services and ensuring the training and education of health professionals and volunteer caregivers in older people’s care facilities are all vital. Increased consideration should also be given to the many young people who are caring for ageing grandparents, who are co-carers, particularly in sub-Saharan Africa, with a focus on their needs as young carers.

In addition, there needs to be increased research on the needs of older people, the benefits of palliative care particularly and effective models of service delivery in developing country settings. These issues will be highlighted on World Hospice and Palliative Care Day – 12 October 2013.

### *Nurse-prescribing of opioids*

Task-shifting has been well-reported in relation to nurse-prescribing in Uganda and we are seeing progress in South Africa too. In countries, such as Sierra Leone, where there are 0.016 doctors for every 1,000 people<sup>37</sup>, the importance of task shifting cannot be over-estimated. Nurses and clinical officers must be empowered to provide quality care, including the ability to prescribe opioids to those who need them. We have

evidence from Uganda that this has not resulted in diversion or poor clinical practice<sup>38</sup>, but rather has ensured that more people can access the care that they need. This needs to be replicated.

#### ***Engaging communities and supporting community caregivers***

In sub-Saharan Africa, 90% of the people living with HIV are cared for by women and girls in the community<sup>39</sup>. Their role has not been limited to bedside care, it has increasingly grown to include economic, social, physical and psychological support. Around the world family and community carers are a fundamental part of the palliative care team to provide effective and quality care, where they are trained, supported and mentored in their caring role. Examples of this includes the Neighbourhood Network in Palliative Care in Kerala<sup>40</sup>.

#### ***Integrating access to palliative care and pain treatment into primary health care***

The challenges of reaching those who need pain treatment where health systems are weak, remain. In order to ensure sustainability of access to pain medications in primary health care settings and hospitals, health professionals in all settings need to be trained and equipped in prescribing them. The Government of Kerala integrated palliative care into their primary health care in 2009, and was probably the first government to do so in the world.

#### ***Addressing the myths and misconceptions***

To make progress in the availability of palliative care and pain treatment, the myths and preconceptions need to be addressed. Access to palliative care and pain treatment is a human right, it is not a luxury for the few. Much must be done to tackle the attitudes of health professionals on prescribing opioids, policy-makers on developing enabling policy environments and the perspectives of the public in order that they demand palliative care services and access to pain treatment.

#### **Conclusion**

Lack of access to palliative care and pain treatment continues to cause distress and suffering around the world. Yet, existing policies and models of practice show that palliative care can be provided to those who need it, inexpensively, significantly improving standards of care and quality of life of people with life-limiting illness. There needs to be significant focus, commitment and investment to improve access to palliative care services worldwide, including medications for the treatment of moderate to severe pain. ●

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