Injustice of access abyss in palliative care and pain relief - a global health failing

Submitted by ncd-admin on 3 February, 2018 - 15:29
Language English



Dr Felicia Knaul speaks with patients © University of Miami

We live in a world where more than 61 million people – including more than 5 million children – experience serious health-related suffering that could be alleviated by palliative care. These are the patients most often neglected as they are too ill to advocate for themselves, particularly at the end of life. The vast majority live in low- and middle-income countries and lack access to even the most essential and basic pain relief...Indeed, the poorest 50% of our world's inhabitants have access to only 1% of the opioid analgesics, while the richest 10% of the world's population receive nearly 90% of the opioid pain relief medication distributed worldwide.[1]

> *...the global health community has not seized the opportunity and responded to the ethical imperative to close the access abyss in the relief of pain and other types of suffering both at the end of life and across the life course.*

A Failing of Global Health

Every year over 25 and a half million people die with serious health related-suffering (SHS) associated to life-limiting and life-threatening conditions. An additional 35 million live with these conditions and SHS. Palliative care can relieve all or most of this suffering, but unfortunately, the majority of people with SHS live in countries with little resources where palliative care is extremely limited or non-existent.

The cost of alleviating the suffering of these 61 million people who live and die experiencing SHS over 6 billion suffering days? An estimated $145 million per year through an essential package of palliative care and pain relief interventions composed of off-patent medicines, basic equipment, and human resources with core competencies.[1] This amount is similar to the annual budget of one, medium-sized hospital in the USA.

Yet, perhaps more shocking is that the global health community has not seized the opportunity and responded to the

ethical imperative to close the access abyss in the relief of pain and other types of suffering both at the end of life and across the life course. What does this say about our values as a global society? More importantly, how can we change the trajectory of healthcare to prioritise palliative care?

A Commission Calling for Change

In 2004, with the support, guidance and active participation of global and regional experts and Chaired by Dr. Felicia M, Knaul and co-Chaired by Dr. Paul Farmer, we launched a *Lancet Commission on Global Access to Palliative Care and Pain Relief* to generate the evidence-base for addressing two key questions – what is the burden of SHS and how can we effectively and affordably respond to this equity and health imperative? The Commission included leaders from different disciplines such as public health, palliative care, nursing, law, economics, epidemiology, public policy, anthropology, and human rights. After three years of work, research and consensus-building, the Commission published what the Lancet Editor-in-Chief Richard Horton has called a ´landmark report´ titled, "Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage [1]," on October 12, 2017.

The Commission Report lays bare the vastness of this access abyss, the low-cost of resolving it, and the strategies to successfully achieve universal coverage of palliative care. Specifically, the report quantifies the global burden of SHS associated with a need for palliative care and pain relief, measures the unmet need for the most basic pain relief medication – morphine, designs and costs an essential package of palliative care and pain relief health services, and provides a roadmap of national and global health-systems strategies to expand access to palliative care and pain relief as an integral component of universal health coverage.

Translating Evidence to Action

To promote action and ensure accountability, the Commission convened an implementation working group of civil society leaders from global, national, and regional palliative care advocacy institutions, to work with institutions like the NCD Alliance. The group is anchored by the International Association of Hospice and Palliative Care [2] (IAHPC) and its mandate is to translate the findings of the Report into a global advocacy and action strategy. The working group is focused on four activity areas to:

1. develop monitoring frameworks and public accountability tools,
2. support national civil society organizations in their efforts to implement the Commission's recommendations,
3. promote knowledge generation and exchange platforms, and
4. create interdisciplinary and multi-sectoral linkages between the palliative care community and the non-communicable chronic disease (NCD) movement and with those working in broader development and anti-poverty efforts.

Synergising with the NCD Agenda

Much of the burden of SHS is associated with NCDs such as cancer, dementia, cerebrovascular disease, and lung diseases.[1] The expected rise in the burden of NCDs and chronic conditions overall alongside aging populations will generate a growing need for palliative care. It is critical to couple these issues in advocacy and action as they are already interlinked in scope and scale, as evident from the example of cancer control campaigns, policies and programs. The recent integration of NCDs into the global health agenda and its large-scale advocacy network have important lessons to help better integrate palliative care and pain relief into existing platforms. World Cancer Day can amplify the message that we need to expand access to prevention, treatment, survivorship, rehabilitation AND palliation for cancer.

One of the main recommendations of the Commission is the convening of an interinstitutional initiative to establish a financing platform for palliative care and pain relief, with a special and immediate focus on children, many of whom have cancer, in low income countries. The fund would aggregate demand and support negotiations to secure low and stable prices for countries with limited resources, particularly for injectable and oral, immediate release morphine. The World Bank, a global financing facility, has the mandate and expertise to lead the efforts alongside UNICEF and the World Health Organization, with the support and guidance of the civil society organizations such as IAHPC and the International Children's Palliative Care Network [3]. Such global collective action would provide the basis and foundation to catalyze the same for treatment of chronic and non-communicable diseases for children as well as adults. This would also be in alignment with the sustainable development goals.

Organisations working on global health strategies and policies, palliative care, and NCD communities, must collaborate urgently to prevent and relieve the suffering of millions of patients. This includes the very sick and fragile children around the world, many of whom have cancer. We calculated that providing pain relief to all children in low-income countries would cost USD $1 million per year. Relieving this suffering is not an issue of cost, but rather depends on political will which can be solved quickly if those with the power to do so take the step forward.

When global leaders convene at the United Nations in New York in September 2018 for the third High-Level Meeting (HLM) on NCDs and agree upon targets, one target must be to immediately relieve the serious health related suffering, experienced by adults and children, globally! Adequate and appropriate human resources as well as safe supply chain management can allow us to achieve this target without delay and serve as an example of the power of collective action to improve the health and quality of life of the most vulnerable among us – individuals experiencing needless suffering.

Join the Movement for Universal Palliative Care

The Commission Report is available online free of charge along with accompanying editorial, "A milestone for palliative care and pain relief [4]" by Lancet editor-in-chief Richard Horton. The recent NCD Alliance webinar [5] featuring Dr. Knaul provided an overview of the major findings and recommendations of the Report. Additional resources such as factsheets and links to media coverage are available at www.miami.edu/lancet [6].

> *World Cancer Day and other occasions marking major health issues serve as an opportunity to be informed, raise awareness and to unite to address the gruesome injustice of the access abyss in palliative care and pain relief!*

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[1] Knaul FM, Farmer PE, Krakauer EI, et al on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. *The Lancet,* 2017. Accessible at: http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32513-8/fulltext [1]

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