**2014-15 PNDP-Open Society Foundations Workshop**

**Documenting Palliative Care and Access to**

**Pain Medications for Children and Adults in Kenya**

**The Context**

It is estimated that more than six billion people worldwide lack access to adequate pain relief. Opioid analgesics, including morphine, are considered essential medicines by the World Health Organization, yet 85 percent of the world’s population consumes just seven percent of the global annual use of pain medications. It is estimated that these low- and middle- income countries account for 70 percent of cancer deaths and 99 percent of HIV/AIDS deaths, two of the most common illnesses that result in intense, end-of-life pain.

In Kenya, it is estimated that deaths from cancer and or HIV/AIDS results in about 85,000 deaths annually, with an estimated 51,000 of those spending their last months in moderate to severe pain. Based on the amount of pain medications that the Kenya Medical Supplies Agency ordered through the International Narcotics Control Board in 2012, and assuming an average dosage of x of morphine for the last three months of a person’s life, only two percent of the 51,000 deaths are treated with adequate pain medication, leaving more than 49,000 to spend their last months in unnecessary suffering.

Because developing countries like Kenya lack much of the necessary health infrastructure for early diagnosis, diseases such as cancer are only diagnosed in their advanced stages (about 80 percent of cancers in Kenya), often beyond treatment.

In its 2010 report, *Needless Pain*, Human Rights Watch estimated that hundreds of thousands of children in Kenya suffer from illnesses that leave them in extremity. Even the youngest experience tremendous suffering, as a July 2014 *British Journal of Medicine* article stated that most of the procedures performed in the neonatal wards of Kenyan hospitals were performed without analgesics.

Pain is an individual and isolating, interior and unsharable experience. Elaine Scarry has written that “pain decontextualizes, it breaks the sufferer away from all other dimensions of this world.” Many have written of the lack of a vocabulary to describe pain. Virginia Woolf noted that if there were a language for pain, it would have to be obscene. Doctors often treat the disease or wound, losing sight of the person suffering from the disease or wound – a template of pain rather than a person in pain.

Treatment for pain, access to opioid analgesics such as morphine, is in itself accessible and inexpensive. Morphine is considered the most effective treatment for severe pain – it is safe, effective, plentiful, inexpensive, and easy to use. It can also do the most to relieve suffering and may also extend survival. The World Health Organization classifies oral morphine as an essential medicine, as does Kenya’s own drug policy. Yet the Kenyan Government does not purchase nearly the amount it needs annually. It is estimated that less than ten percent of Kenya’s 250 hospitals have access to morphine.

According to the Treat the Pain initiative, a web of barriers force millions to live and die with treatable pain. These barriers include legal and regulatory restrictions, cultural misperceptions about pain, stigmas and taboos attached to death, inadequate training of health care providers, poorly functioning pharmaceutical markets, generally weak health systems, strict drug trafficking laws, and concerns about diversion, addiction and abuse.

But treating the pain itself is often not enough. Palliative care – preventing suffering and improving the quality of life – needs to become a necessary component of the health system, especially for children. Palliative care, common in countries like the U.S., is just developing in many low- to middle-income countries and is often focused on adults.

In its report, Human Rights Watch calls for the active and total care of the child’s mind, body and spirit.

Through non-fiction, narrative storytelling and by working closely with the individuals affected by and invested in Kenya’s policies on access to pain medication and the provision of palliative care, the Program for Narrative and Documentary Practice at Tufts University seeks to add a human face to these challenges and raise governmental, medical and public consciousness and action.

**The Project**

Working under the close guidance of professional photographers, videographers and writers, six students from Tufts University will be paired with a mix of six photojournalism students and young photographers in Kenya to collaborate on a series of character-based, multimedia narratives that work to convey the extremity children and adults face in living with life-threatening diseases without access to pain medications, as well as the current extent of palliative care, in Kenya. Our hope is that medical professionals, government officials and activists in Kenya and beyond will be able to use these narratives in their campaigns to expand palliative care and break the logjams that currently prevent access to pain medications.

In addition to raising the consciousness of the government, the medical community and the public about the need for access to pain medicines, this project will also engage students from Kenya and the US in cross-cultural learning and collaboration and develop their skills in non-fiction, narrative storytelling and photography.

**Particulars**

• The workshop will take place in Nairobi.

• The dates of the workshop are August 18-29, 2015 (could move one or two days either way).

• Participants are expected to arrive in Nairobi by August 18 (usually means leaving on .

• The workshop will cover air travel, local travel in Nairobi for the workshop, accommodations, and a local phone for workshop use.

• Participants will be responsible for their meal costs and any other incidentals.

• Built into the workshop are days to do final edits of work – final cuts/edits of photos will be due on the 29th along with at least a polished rough draft of all written work and a rough cut of video.

• There will be a final editing process that continues into September that participants will be expected to contribute to in a timely way.

For any questions, please contact:

**Heather.Barry@tufts.edu** **or** **Samuel.a.james@gmail.com**



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**tuftsgloballeadership.org**

**APPLICATION**

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**Documenting Palliative Care and Access to**

**Pain Medications for Children and Adults in Kenya**

***The workshop is looking for students interested in writing, photography and/or videography.***

**A/Information**

Name:

Tufts ID#:

Preferred Email Address:

Phone:

Graduate or Undergraduate (circle one) Graduation Year: 201\_\_

Major(s):

Minor(s):

Do you own a DSLR camera? YES NO (circle one)

Do you speak Swahili? YES NO (circle one)

What courses have you taken related to writing, photography, or videography?

What courses have you taken related to the place and/or topic of the workshop?

Are you most interested in (circle all that apply):

Writing Photography Videography

**B/Travel Questions**

Have you traveled outside of the U.S.?

If yes, where have you traveled?

Which locations were for vacation?

Which locations were for study abroad, internship, research, volunteer work, or other similar purpose (and what was the purpose)?

For any of the travel, did you go independently or with someone/a group?

Pick one location. What stood out for you the most during that experience?

**C/Questions**

Why do you want to participate this workshop? What do you hope to gain from the experience?

What previous experience do you have with narrative storytelling (in photography, writing, film and/or radio broadcast)?

What do you think you would contribute to the workshop?

What are some of your initial thoughts about possible approaches to telling stories about the theme of the workshop?

**D/Sample Work**

In addition to the application questions below, please also email a sample of your previous narrative work. Submissions can include any, or a combination, of the following:

- 1500 (or more) word written essay

- 20 image photo essay, including captions and overview of the story

- Short film or video

**Application Due: April 15, 2015 by 9:00pm**

**Send to**

**Samuel.a.james@gmail.com** **and** **heather.barry@tufts.edu**

**Application Interviews: April 27-29, 2015.**

**You will be contacted after submitting your application.**

**Selections will be made by April 30, 2015.**