Who's Afraid of Cervical Cancer?

By Lisa Furmanski, MD

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I February 2019 LF spent one week going on home visits with Rays of Hope Hospice Jinja after which she wrote this article.

It is seven o'clock and the Rays of Hope Hospice Jinja nurse is on her rounds, looking for her final client. Already lost twice and the car stalling at an abandoned intersection, her clients have no actual address, where each lives is relative to somewhere else — a fork in the path, a brick stack where the goat sleeps, a chapati stall. At last, the car sways up a crest to a squat house where a young woman on the floor is dying of cervical cancer.

Cervical cancer is a terrifying diagnosis in Uganda. As the cancer grows, it invades and expands. Invasion creates fistulas, painful tracts connecting vagina and bladder and bowel to the outside so fluids trickle down her legs. The cancer oozes, soaking through rags wrapping her body. Expansion creates blockages, the pressure excruciating.

The RHHJ nurses' day begins in prayer, with a song pulsed by drumming. The team reviews the clients to be seen, they plan bereavement visits for those who have already died, they consider food and housing and school fees for the destitute. Medication boxes are packed in suitcases, bottles of liquid morphine nestled in a shopping bag next to liters of water to drink in the heat.

Grimacing, a young woman props herself on tiny elbows to bestow a proper greeting. For weeks she will not leave her room. For days she will not eat in order to minimize the smell. The nurse refills the client's pain medication, she counts out antibiotics to crush and sprinkle in the wounds for the odor. The nurse reviews hospital papers which document the limits of treatment options and costs which are prohibitive.

In the developed world, cervical cancer is a diminishing disease; with widespread PAP smear testing, precancerous lesions are diagnosed and treated early. And the HPV vaccine has the potential to eradicate the virus from future generations. Last year, the Director-General of the WHO called for elimination of cervical cancer, and the World Health Assembly in 2020 plans to draft a strategy to do so. But a recent Lancet article describes a predictive model in which this is only achievable with immediate intensive screening and HPV vaccination.

In a recent Lancet editorial, researchers state that cervical cancer is "not a disease of the past — it is a disease of the poor." Cervical cancer is the most common cancer of women in Uganda. Eighty percent of these women present with advanced disease, and only twenty percent will survive 5 years; the rates continue to rise despite small attempts to expand screening and vaccination.

The statistics, while alarming, do not do justice to the incredible suffering that this cancer inflicts, and do not begin to illustrate the final months of a woman dying of cervical cancer. As cervical cancer declines in high income countries, its potency in the imagination of donors and researchers and experts may soften — what will keep these women in our sights?

A Rays of Hope nurse tells us the story of a woman with such intense bleeding from her cancer, it had stained every item in the home, the smell driving her daughters from her room, and she lay on a mat, using whatever cloth she could find. The nurse had delivered a sack of rice and beans, and he relayed her joy in this small support. A colleague points out that this same nurse had broken down only a week earlier after visiting cases. He had cried in the car and told his colleague that sometimes it is "too much to see."

Over the past twenty years, we have witnessed the transformation of the AIDS epidemic in Uganda with the arrival of anti-retroviral therapy (ART). Many of the nurses that provide care to women with cervical cancer are veterans of that battle. They recall their communities before and after the introduction of ART — the weeks with a burial every third day now replaced by healthy clients who pick up medication every three months. Many of us also

remember when ART in a low resource setting seemed nigh impossible, but with concentrated expertise and funding the epidemic changed course. One nurse asks, “Can we not do the same for cancer of the cervix?”

What do they need next? Their young daughters need the vaccine urgently (a campaign in 2016 reached only 20% by some reports). Their older daughters need vaccination, home-based screening, and widely available and affordable treatment. They need careful language that respects and engages their plight even as wealthier nations move on.

What do they need right now? Honestly, thick diapers and sanitary pads, morphine and stool softeners. They need a health team to visit them at home, they need to die with comfort and dignity. The AIDS epidemic has shown what is possible, these too are possible. And the nurses are ready.