2nd Annual Conference Summary 2018

Background

Cancer is the leading cause of death globally, yet millions of people could be saved from premature death or cancer-related morbidity if early detection and treatment initiatives were implemented in conjunction with targeted prevention activities. Cervical cancer in particular constitutes an overwhelming proportion of the worldwide oncological burden. While it is one of the most preventable cancers, it is one of the greatest impediments to promotion of women's health effecting over one million women worldwide. [1] According to the World Health Organization, the majority of cervical cancer cases remain undiagnosed, and of the 528,000 new cases diagnosed in 2012, nearly 90% live in low- to middle-income countries[1]. Thus, cervical cancer is the leading cause of cancer-related death in resource-limited countries.[2] Projections state that, "without urgent attention, deaths due to cervical cancer are projected to rise by almost 25% over the next 10 years."[1]

Almost all cervical cancer results from the sexual transmission of the Human Papilloma Virus (HPV). HPV is the most common sexually transmitted infection (STI), and exposure usually occurs within one year of sexual debut.[3] Cervical cancer outcomes are uniquely responsive to a variety of comprehensive public health interventions that address areas such as infectious disease control, community-based health education and chronic care delivery systems. Countries with well-organized programs to detect and treat early stage cervical cancer can prevent up to 80% of related morbidities.[4] incorporating a multifaceted approach such as this can yield public health benefits that directly affect families, communities and the nation.

The incidence and mortality of cervical cancer in Haiti is among the highest in the world. Haiti has a population of 3.64 million women ages 15 years and older who are at risk of developing cervical cancer. Current estimates indicate that every year 1,048 women are diagnosed with cervical cancer and 575 die from the disease. Cervical cancer ranks as the most frequent cancer in women between 15 and 44 years of age and the most common cancer in women overall. Data is not yet available on the HPV burden in the general population of Haiti. However, in the Caribbean, 15.8% of women in the general population are estimated to harbor cervical HPV-16/18 infection at any given time, and 60.2% of invasive cervical cancers are attributed to these two HPV subtypes.[i]

Haiti sans Cervical Cancer (HsCC) Consortium

The Haiti sans Cervical Cancer (HsCC) consortium is an alliance of partners who are committed to working together and supporting Haitian medical leadership in their efforts to create a national cervical cancer prevention program. The first meeting was held in October, 2015 in Durham, North Carolina. HsCC was officially incorporated in November, 2015 with 10 NGOs (Non-Governmental Organizations) on its roster.

The mission of HSCC, in partnership with the Haitian Ministry of Health, is to reduce the burden of cervical cancer in Haiti. To accomplish this mission, HsCC hopes to:

1. Coordinate partnerships with both government organizations and NGOs
2. Support cervical cancer prevention efforts of Haitian NGOs
3. Assist Haitian leadership in their efforts to develop a national cervical cancer prevention program

In this process, HsCC hopes to employ a comprehensive approach, and advocate not only for the development of a national system that supports women's health, but also one that focuses on prevention, screening, and treatment of all stages of cervical pre-cancer and cancer. To accomplish this we must:

1. Expand community education and awareness campaigns in the Haitian general population and among health care providers, with an emphasis on reproductive health and the importance of HPV and cervical cancer

2. Incorporate this knowledge into medical education and training programs.

3. Help make the HPV vaccine available to the growing youth population of Haiti.

4. Train local providers in how to screen and treat cervical pre-cancer

5. Expand education and training on cervical cancer treatment

We must not forget that mortality from cervical cancer, which is preventable, now exceeds maternal mortality in many low resource countries. This message needs to be echoed on the global health stage and the prevention of cervical cancer needs to become a worldwide health priority.

The NGO community has the potential to be a great resource in Haiti and it needs to unite and focus on supporting the Haitian Ministry of Health (MSPP), the Haitian Ob Gyn Society (SHOG), the Haiti arm of JHPIEGO and the Groupe de Support Controle le Cancer.

Conference Day 1

The second annual Haiti sans Cervical Cancer (HsCC) Conference was held on June 28th, 2018 at the Hotel Montana in Port au Prince, Haiti. The HsCC Conference reunited a variety of key stakeholders from the public sector, such as the Haitian Ministry of Health (MSPP); non-governmental organizations (NGOs); and cancer centers including Dana Farber Cancer Institute and Sylvester Comprehensive Cancer Center as well as bi-lateral and private partners.

The conference was launched with welcoming remarks by Dr. Leslee Jaeger, Board Chair for the HsCC consortium. This was followed by an impassioned speech by keynote speaker, Didi Bertrand, MA, DEA, DESS, whose mother lost her battle with cervical cancer at a young age.

Representatives from HsCC, Sylvester, and USAID then presented recent interventions and key findings in research related to cervical cancer. The presentations included:

- Serge Michel and Elizabeth Campa, MsC (HsCC, Zanmi Lasante) shared the successes and challenges of a HPV vaccination program in the Central Plateau and Lower Artibonite regions
- Rachel Masch, MD, MPH (HsCC partner, Basic Health International) reviewed data demonstrating the cost effectiveness of a national primary HPV screening program in El Salvador
- Erin Kobetz, MD, MPH representing HsCC and University of Miami PhD candidate Rhoda Moise introduced their work on a cervix screening registry that was created for Haiti with support from the Sylvester Comprehensive Cancer Center;
- Ilana Lapidos-Salaiz, MD, MPH from USAID highlighted key trends in global funding for cervical cancer prevention.

In order to address particular key interests, the conference participants separated into break-out sessions that covered four topics: 1) HPV vaccination; 2) cervix registry; 3) screening and treatment guidelines; and 4) palliative care for cervical cancer. The following sections are short summaries of what was discussed in each break-out session group.

HPV Vaccination

This break-out session group discussed the importance of finding resources and sharing lessons learned with the Haitian Ministry of Health (MSPP). The participants also touched upon the importance of involving the DEPEV, the MSPP's department for vaccinations, during any HPV vaccination campaign to ensure compliance with national standards and protocols. The group also discussed how ZL could share resources from their experience with their HPV campaign to key partners to standardize documents for the administration of HPV vaccines. It was agreed that medical personnel and community health workers (CHWs) should all complete a training process before beginning vaccination and education campaigns. HsCC's consortium partners would greatly benefit from ZL's documents and Terms of References on cervical cancer and vaccine administration, given the organization's successful campaign. One challenge many organizations face is how to pay to store HPV vaccines; approaching GAVI for their support with HPV vaccination could ease some of these monetary difficulties and enable organizations to pursue future HPV vaccination campaigns.

HPV Vaccination Actionable points:

1. Create a list of partners interested in conducting a HPV vaccination campaign
2. From the list of partners interested in vaccination, map out in which region each institution is working and what kind of support they have
3. Follow-up with GAVI for their support
4. Discuss with HsCC how to update their website and use other social media platforms to highlight relevant HPV vaccination information
5. Send details of each organization's background and the population they target
6. Share relevant information with HsCC partners about ZL's HPV campaign, scheduled October 22-26th, 2018

Update

On Friday, July 20, 2018, HsCC board members, Dr. Rachel Masch and Elizabeth Campa had a phone meeting with the Global Alliance on Vaccination and Immunization (GAVI). While the conversation was an opportunity for a first ever dialogue between HsCC on behalf of partners throughout Haiti interested in conducting HPV campaigns, the HsCC board members were very happy with the dialogue and suggestions moving forward which included:

1. Letter to the CEO, Board Chair and Deputy CEO of GAVI explaining the consortium, why now and not later when Haiti can meet the DP3 coverage requirement, statistics, as well as cervical cancer rates, particularly if the rates continue to rise, it will take so much longer to eliminate and so many more lives needlessly lost.
2. Develop a model for the cost of inaction including cost of treating disease burden compared to vaccination. What would happen if we do not intervene now and wait 5, 10, 20 years.
3. Share details of successful HPV campaigns that have already taken place in Haiti.

Cervix Registry

Participants in this break-out sessions discussed how the establishment of a cervix registry would provide clear benefits to the MSPP and the HsCC partners. The registry would enable multiple sites to track patients using unique ID numbers, with information on patients such as their names, birthdates, address, and other key demographics. Some challenges that the national cervix registry faces is conversion to an electronic record, since paper charts remain the standard in many areas. Another challenge to the registry is the funding needed for a technical advisor and data entry support. The break-out session group asked the question regarding how women can own their data.

Cervix Registry Actionable points:

1. Suggestions for improvements to REDCap and the platform for the cervix registry, including using Excel

2. HsCC and its partners should revise their pregnancy variables (Gestation, Pregnancy, Abortions), and develop a minimum required viable data set (i.e. 98 refuse, 99 unknown)
3. Create the ability to generate annual reports by HsCC and its partners, for example by national region or organization
4. Test registry with a pilot group to troubleshoot problems with any of the questions or response options (i.e. can input patient data from ZL or other HsCC partner(s) existing patient database)

Screening and Treatment Guidelines

This break-out session touched upon topics such as barriers to implementing HPV vs. VIA programs, screening and treatment methods, as well as screening protocols. The group determined that the largest perceived barrier to implementing HPV testing is the cost, but was inconclusive on defining a justifiable price that would entice more women to come into clinics for testing. Compared to a Pap smear test, which is $30/test, an HPV test that costs $5/test would be reasonable if women knew they wouldn't have to take another test for five years. It was also discussed that women can easily perform self-sampling with HPV, but a lab would be needed to process the samples and provide the results. The institutions represented in this group offer several screening and treatment options for premalignant/malignant cervical disease including: VIA, colposcopy, cryotherapy, LEEP, cone biopsy, and radical hysterectomy. The World Health Organization (WHO) recommends several strategies for screening and treatment: 1) Screen with HPV, and positive cases receive cryotherapy if advanced disease is excluded (HPV test and treat) 2) screen with HPV and if HPV is positive, do a second screen with VIA, and treat only if BOTH are positive and there is no evidence of advanced disease 3) in resource-constrained settings, where screening with an HPV test is not feasible, screen with VIA and treat if there is no evidence of advanced disease. MSPP oncology representative recommends VIA and Pap tests, but in this group there was more support to move away from Pap tests secondary to costs and high rates of false negative and false positive results.

Screening and Treatment Actionable points:

1. Create a map using conference registration information of all the HsCC partners and the intervention(s) each organization is/are doing. This will allow better information about where and what is being offered in Haiti and increase coordination among the sites.
2. HsCC will post on their website conference presentations, map of partners, and helpful articles
3. Participants are invited to leave comments on the HsCC website about what could be helpful to cover at next year's conference
4. Organize next year's HsCC conference around the availability of MSPP representatives

Palliative Care for Cervical Cancer

This group defined palliative care as improving the quality of life for the patient, family and community during the late stages of cancer. The components of a palliative care program should be a trained team comprised of a supervising physician, a nurse or community health worker, a social worker, and a psychologist. The group talked about the important components of a palliative care program and different strategies for getting one started and advancing its reach. The core message was not to be afraid to start. Women who are dying in pain and social isolation need to be loved with compassion where they are even when we think that we don't know how. The group also discussed different ways of mentoring new palliative care programs ranging from visiting existing sites to inviting hospice care providers to teach.

Infection / odor management: It was suggested that vaginal metronidazole and perineal care can reduce anaerobic infections that are associated with a strong odor.

Bleeding management: Minimizing physical manipulations of tumors is one of the keys to minimizing bleeding. More effective would be radiation therapy but these services are not yet available in Haiti.

Social support: Often times when patients are in their late stages of cancer, they prefer to isolate themselves from society. Mental health is important to address, and a psychologist and/or social worker can play an important role for patient, family, and community relationships. Other than the physical needs directly linked to cancer management, social workers can also support the needs of family, friends and the community through financial, nutritional and other necessities.
End of life planning: Lastly, palliative care is a time to communicate about the end of life transition for patients. This requires an individual to discuss these sensitive topics in an appropriate manner.

Palliative Care Actionable points:
At the end of the break-out session, there were no actionable points suggested by the group other than to establish a group that will communicate over the next year. Only two participating organizations had palliative care experience: Zanmi Lasante and MediShare. There was a consensus that all of the current palliative care in Haiti was at a relatively early stage and that it is important for all stakeholders to learn together. The group talked about the important components of a palliative care program and different strategies for getting one started and advancing its reach. The core message was not to be afraid to start and not to be afraid to make mistakes. The group also discussed different ways of mentoring new palliative care programs ranging from visiting existing sites to inviting hospice care providers to teach.

Conference Day 2
Day two of the HsCC 2nd Annual Conference focused more on dialogue on topics such as HPV testing and costs, as well as which of the four pillars of HsCC (vaccination, screening and treatment, registry, and palliative care) were of highest priorities. The participants represented a variety of organizations, local and international, all of which shared their own unique perspective on HPV costs. With over 80% of the Haitian population living on $2/day or less, many institutions have encountered that even 50 HTG (less than $1 USD) is not affordable for patients when factoring in fees for transportation and food. Arguments were made that HPV testing should be free, and others believed that patients should pay on a sliding scale, determined by their economic status. Voluntary contributions is a strategy used by one organization that provides free VIA screening once a month at their clinic. Others have charged a small fee for their services, but patients had to pay for medicines, versus charging a higher rate, but including medicines within the fee. It was discussed that some women may feel a sense of pride in paying for their HPV test, while others may not be able to afford it. There are many strategies that have been implemented across the country by various organizations. The overall conclusion was that it was difficult to charge one universal price for HPV testing because the economic circumstances of patients are too vast to create a standard cost. Each place had to arrive at a strategy that made sense for the communities in which they work.

The second part of the discussion surveyed what the participants believe was most important among vaccination, screening and treatment, cervix registry, and palliative care. After each participant shared their viewpoints, the majority stated that screening and treatment as well as palliative care were important. Although vaccinations are a preventative measure to HPV, it's much more expensive for organizations to supply and implement vaccinations as compared to the costs of screening and treatment. Many Haitians go to the hospital when they are in the late stages of cancer. There is no radiation therapy available in Haiti, and palliative care, when available, can be provided to patients who are suffering. Zanmi Lasante's Hôpital Universitaire de Mirebalais (HUM) is training residents on palliative care, which could perhaps result in a developed model. Education is also an important element that crosses each of these four pillars, but it was also mentioned that understanding cultural beliefs of the population is just as important prior to any

intervention. In conclusion, it's difficult to determine which pillar should be prioritized as they are all important, but the group consensus was screening and treatment as well as palliative care were most pertinent.

Media Sources

The HsCC Conference was covered by all media sources, including Le Nouvelliste, Le Tele National Haiti (TNH), and Tele National Ginen (TNG). In addition, Miami Herald's Jacqueline Charles attended the conference, and will be doing a series this August on cervical cancer.

Acknowledgements

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[1] **World** Health Organization. (2014).1. *Comprehensive cervical cancer control- a guide to essential practice second edition*. Switzerland: WHO, 7.

[2] Sherris, J., Herdman, C., & Elias, C. (2001). Cervical cancer in the developing world. *The Western Journal of Medicine, 175*(4), 231.

[3] World Health Organization. (2014).1. *Comprehensive cervical cancer control- a guide to essential practice second edition*. Switzerland: WHO, 3.

[4] World Health Organization. (2009). Weekly epidemiological record.*84* (15), 118.