

The Inaugural Caribbean Cancer Survivorship Conference 2016

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Abstract-The Inaugural Caribbean Cancer Survivorship Conference held on October 21-22, 2016 provided a forum to discuss strategies and solutions to reduce the burden of cancer on both the patient and their communities. The event was structured around seven short presentations delivered by experts from the Caribbean and internationally, testimonials from cancer survivors, and question and answer sessions to encourage the audience to interact with the presenters, as well as a conference evaluation questionnaire. *Conference presentations focused on the significance of survivorship to the delivery of care to cancer patients. Specific topics included the History of Breast Cancer; Cancer Research Statistics in the Caribbean; Cancer Survivorship Models and Care Plans; Perceptions, Myths and Mysteries that Impact Breast Cancer; and Hope and Empowerment for Survivors.* Analysis of the conference evaluation forms pointed to/highlighted that patients and survivors require greater and improved cancer surveillance, integrated medical care regionally and internationally, psychosocial support, and improved information and resources for self-care following treatment such that their quality of life can improve and be sustained. The participants found the seminar to be very informative and significant as it related to the issues related to surviving cancer and quality of life. Strong recommendations were made for similar conferences, possibly annually, with the inclusion of a greater number of cancer survivors in attendance (including regional and international cancer support groups, cancer survivors attending public oncology units, etc.).

Index Terms- Cancer survivor, Cancer Survivorship, Diagnosis, Management of Cancer and Treatment Options in the Caribbean.

I. INTRODUCTION

The Inaugural Caribbean Cancer Survivorship Conference was a collaborative event between the University of Trinidad and Tobago (UTT), Cancer Survivors in Action (CSIA), City of Hope and the Healthy Caribbean Coalition (HCC). The Conference was held on Friday 21st October, 2016 at The National Academy of Performing Arts (NAPA), Port-of-Spain, Trinidad; and Saturday 22nd October 2016 at Ortinola Great House, Maracas, St Joseph, Trinidad. This Conference was the first to be hosted on the topic of Cancer Survivorship regionally.

An additional component to the Conference was a Cancer Survivors Forum hosted by NCD Alliance and the Healthy Caribbean Coalition (HCC). This discussion allowed researchers to better understand the disparities and barriers related to survivorship care.

Speakers for this Conference included: Dr. Charusheela Andaz, Breast Surgeon affiliated with Maimonides Medical Center in Brooklyn; Dr. April Barbour, Internist/Associate Professor of Medicine with The George Washington University School of Medicine and Health Sciences; Dr. Rita Strickland, former Chair of the Nursing Department at New York Institute of Technology; Ms. Kimberly Badal, Director of Caribbean Cancer Research Initiative (CCRI); Dr. Agatha Carrington, Assistant Professor/Program Leader, Master's in Health Administration (MHA),UTT; Dr. Bernadette Sheridan, Founder/Family Practitioner at Grace Family Medical in Brooklyn; Ms. Jasmin Holder, RN, Case Manager, Founder/President of Care Masters LLC and Dr. Shevon Joseph, Physician in the Department of Obstetrics and Gynecology at the NYU Lutheran Medical Center in Brooklyn, NY.

In 2013, the World Health Organization (WHO) advised that Cancer is a priority in the Caribbean [1]. Prostate cancer is the leading cause of cancer death among males, with 51,000 deaths annually, followed by lung cancer and stomach cancer. Among females, breast cancer is the leading cause of cancer death, with about 43,000 deaths annually, followed by cervical and lung cancer [2]. A review of the *World Health Rankings-Health Profile: Trinidad and Tobago, 2017* indicated that cancer is a priority with the age-standardized death rate per 100,000 population for Prostate and Breast Cancer being ranked 4th and 9th respectively [3]. Across the developing world, cancer has become a major health challenge that needs to be urgently tackled. More than one third of cancers can be prevented and another third are curable if detected early [4].

According to the American Cancer Society Inc (2016) [5], "more than 15.5 million children and adults with a history of cancer have survived in the United States (US) as of January 1, 2016. It is estimated that the population of cancer survivors will increase to 20.3 million: almost 10 million males and 10.3 million females by 2026. Cancer screenings for early detection; promoting healthy lifestyles by attention being focused on reducing obesity, healthy diets, physical activity, and avoiding tobacco; and cancer care through a number of high-profile programs are encouraged to prevent cancer and are instrumental to the continued increase in the cancer survivorship rate in the US [5].

Currently, there is limited statistics on cancer survivorship in Caribbean countries, and there exists a great need for research to be done in this area. The barrier of non-existent/non-functioning cancer registries and government statistical agencies is a limitation to obtaining this data; and hampers the the design of

credible cancer plans, including initiatives for primary prevention [6].

Healthcare Professionals world-wide have been searching for ways to deal with the effect that cancer is having on their societies. In an attempt to avoid and arrest the late effects of cancer and to ensure the best possible outcomes for cancer survivors, fostering healthy communities, prepared patients, responsive health care professionals and supportive health care systems through applied cancer research, education, advocacy and translation of evidence to practice was recommended, according to Institute of Medicine and National Research Council (2006) [7].

The HS&HAU, UTT has been striving to improve the cancer care continuum in the Health Sector of Trinidad and Tobago. In support of Breast Cancer Awareness Month worldwide and Cancer Awareness Month in Trinidad and Tobago (held annually in October), the Conference brought together a host of Healthcare Professionals including government ministers, oncologists, oncology nurses, surgeons, other medical practitioners, NGO's, international stakeholders and cancer survivors. It was structured around presentations to encourage all participants to enter into discussion on the issues related to survivorship and patient navigation in Trinidad and Tobago.

The Conference, having regard to the fact that the profile of our population indicates that cancer is a priority, highlighted the existing gaps in the provision of health-care for a growing number of cancer survivors. Gaps highlighted included medical, psycho-social, health policy and economic issues on cancer survivorship; networking and building collaborations with cancer specialists, oncology professionals, cancer supporters, and cancer survivors from the region and internationally.

II. SCIENTIFIC PRESENTATIONS

The Chairman of the University of Trinidad and Tobago, Professor Kenneth Julien, spoke on the importance of hosting a Conference such as this. He spoke to the role of healthcare management, which includes improving affordability and quality of service offered by healthcare professionals. He indicated that to ensure management of the health sector was up to standard, there must be up-to-date databases for decision making. He also spoke on the issue that there should be improved training available to clinicians and information should be made available to patients so that they can help manage their care.

DAY 1: Friday 21st October, 2016

Presentation 1 - Technical Advances in Breast Cancer - What is to be expected on the horizon?

The first Conference presentation was from Dr. Charusheela Andaz who spoke on the Technical Advances in Breast Cancer. In her presentation Dr. Andaz spoke on the Cancer Age-Standardized Mortality Trends over the period of 2000 - 2012 in Trinidad and Tobago, and the intent to decrease the Cancer Mortality Profile by early diagnosis and better screening,

treatment and outcomes. She also noted developments in breast imaging and guidelines for early detection and improved treatments whereby more women than previously are surviving breast cancer in the UK and US.

Presentation 2 - The Role of Research in Improving Cancer Survivorship in the Caribbean

The second Conference presentation was by Ms. Kimberly Badal, who spoke on the continuum of cancer care being a process in which care must be accurate, precise and quick at all stages of the continuum. She highlighted the fact that there are external factors that also influence the success of this continuum and that the role of research as an integral part of our health care system, will assist identifying these factors and move to improve the cancer survival rate in the Caribbean. She presented statistics on Breast and Prostate Cancer Survival Rates in the Caribbean for the period - 2005. There was no current cancer survival information. Ms Badal closed by affirming that research is the foundation of Public Health and Medicine, and this body of research can only be achieved through successful collaborations throughout all sectors of society.

Presentation 3 - Models of Survivorship Care

Dr. April Barbour presented on models of survivorship. She defined the term 'cancer survivor' and the needs of a survivor for a better quality of life. She mentioned the effects of cancer treatment and the need for them to be managed when they do occur. In response to these needs, mention was made of the IOM seminal report "From Cancer Patient to Cancer Survivor: Lost in Transition", which identified gaps in coordinated and comprehensive care; called for care plans to be delivered to all people treated for cancer and called for improved care delivered to patients post treatment.

Dr. Barbour's extensive experience in the field of Survivorship spoke to survivorship care plans as a key survivorship care component, as they serve as a roadmap for post-treatment care and can be used as a tool for care coordination and communication. The survivorship care plan should be created by the patient's treating team and shared with other specialists, primary care providers and the patient. Lastly she spoke to the different models of survivorship care and the integration of these models within the cancer care continuum.

Cancer Survivor Testimonial

The survivor gave her experience surviving cancer. She recalled the discovery of a lump in the nipple of her breast which led her to have an ultrasound done (as she was afraid of mammograms). The result was in concurrence with her family history and other medical facts and she had to proceed further to get a biopsy done. The biopsy results confirmed that she had cancer. She stated that at that moment, she was strong and asked the doctor what she could do to get it out of her body since it didn't belong there.

Two weeks later she had surgery. She also stated that a friend referred her to an Oncologist in Venezuela, whom she immediately made contact with and went to Venezuela. There she ran several tests and the doctor sent her the results verifying it was Stage II Cancer. She returned to Venezuela and started

treatment (this was about six weeks after her surgery). She was pleased with the fact that her treatment included meeting with a nutritionist and psychologist (she discovered eight years later that the same services were now available at the National Radiation Centre, St. James Medical Complex, Trinidad and Tobago). She stressed that INFORMATION WAS KEY which was/is not readily available to cancer patients in Trinidad and Tobago.

Presentation 4 - Focus Group Report of Reach to Recovery Cancer Survivors

This Conference presentation was done by Dr. Agatha Carrington. She started by defining 'quality of life' and then presented a multi-dimensional mapping on the different aspects of quality of life for patients. She shared the findings of her focus group, conducted with members of the REACH FOR RECOVERY GROUP - a support group located at the St James Medical Complex, Trinidad and Tobago.

The themes which emerged from this study, which are in alignment with the social cognitive theory (SCT), include - self-image, acceptance of roles, support, impact on cognitive skills, response or adjustment, symptom distress, all impact the domains of quality of life and. In so far as the assumptions of the SCT (outcome expectations) of patients when presented with a diagnosis of cancer are concerned, these expectations (self-efficacy and self-regulation) influence the physical, psychological, social and functional aspects of the patients' quality of life.

Presentation 5 - Hope and Empowerment for the Survivors

The final Day 1 presentation was by Dr. Rita Strickland on the topic of hope and empowerment for survivors. She spoke to the field of spirituality and its many definitions. She referred to studies where persons who engaged in regular spiritual practices demonstrated decreased levels of stress, better coping mechanisms, richer social support and an improvement in their quality of life.

She also spoke on the role of support groups. Her research evaluating support groups for women with breast cancer, pointed to several benefits which included sharing experiences, preventing isolation, enhancing self-esteem, exchanging information, lending support, providing hope and developing a higher quality of life. Resiliency, mentorship and travel also proved to be effective support systems.

DAY 2: Saturday 22nd October, 2016

Presentation 1 - Women, Cancer, and History

Dr. Bernadette Sheridan presented on the history of breast cancer and how surgery developed (the first mastectomy in 1882). She enlightened the attendees on the discoveries of antiseptics, anesthesia and antibiotics that made the difference in surgery for cancer. By the twentieth century, there were better treatment options which led to extended survival rates.

Presentation 2 - Perceptions, myths and mysteries that impact breast cancer screening, diagnosis and management within immigrant communities in NYC

Dr. Shevon Joseph described Cancer as a slowly developing illness. Once a diagnosis is made certain preconceived notions can limit a woman's ability to grapple with details about treatments like chemotherapy, surgical and radiation options, which at times delays initiation of treatment.

Within the immigrant communities in Brooklyn there are a multitude of barriers that directly impact health care. She highlighted a list of myths, perceptions and mysteries compared with the facts and realities related to breast cancer. One such example given was the ongoing concern that antiperspirants and deodorants cause breast cancer (myth/perception/mystery) compared to the response by researchers (ACS and NCI), that this is merely a rumor and more research is needed to prove otherwise.

Presentation 3 - Empowering the cancer patient - Faith in all options available

This was the last presentation for the Conference with an impacting message on faith and empowerment of the cancer patient delivered by Ms. Jasmin Holder. Due to her experience as a Registered Nurse-Case Manager, she highlighted the importance of a Case Manager's role in improving the efficiencies and outcomes of the patient's cancer care. She outlined goals that would empower the survivor namely to be informed, educated, proactive, well, curious, relentless and to know your rights as a patient/healthcare consumer. She defined faith and empowerment and she listed some essential facts about cancer and medical options for treatment.

III. CONFERENCE EVALUATION

Evaluation forms were distributed for the Conference. Eighty (80) participants attended the Conference and forty three (43) questionnaires were returned. For each session, the relevance of the topic, quality of speaker presentations, and knowledge gained were evaluated using a typical five Likert Scale. Attendees had the opportunity to answer questions rating 0–4 (0 = No Opinion, 1-Strongly Disagree, 2-Disagree, 3-Agree, 4-Strongly Agree). Participants were also asked to provide their comments and feedback in short answers. Overall satisfaction with the Conference and the attitudes toward location, venue facilities and session length were rated.

Figure I: Bar Graph showing Participants Overall Satisfaction with the Conference

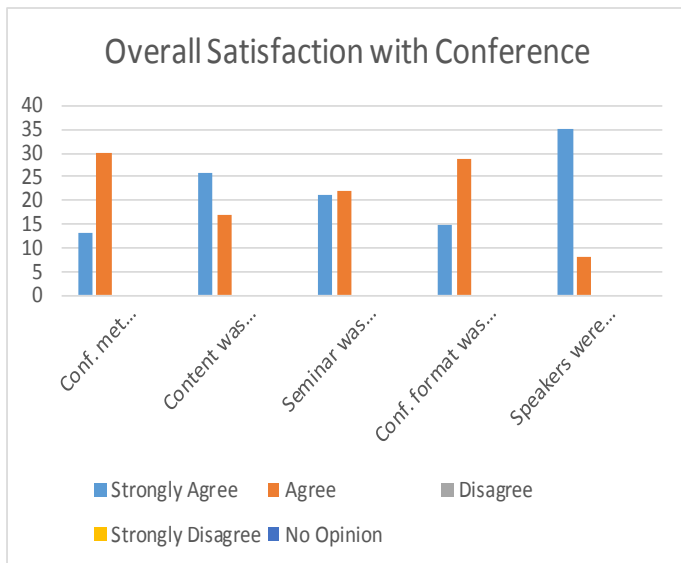


Figure II: Bar Graph showing Participants Satisfaction with Length, Location and Location Facilities of the Conference

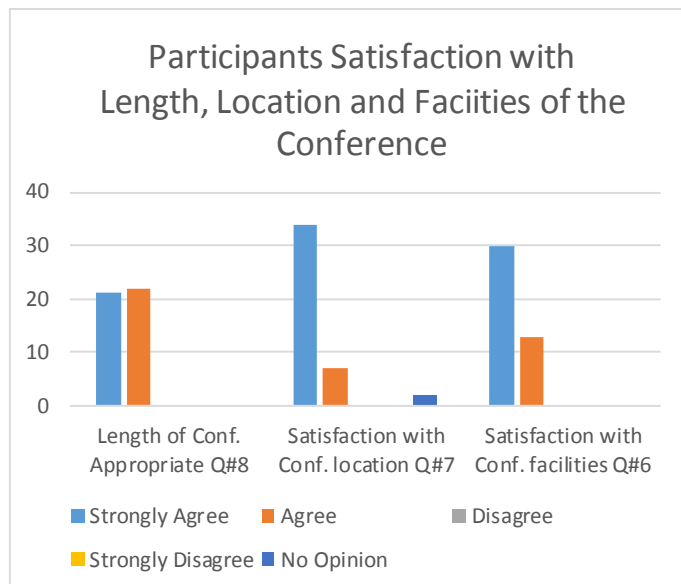
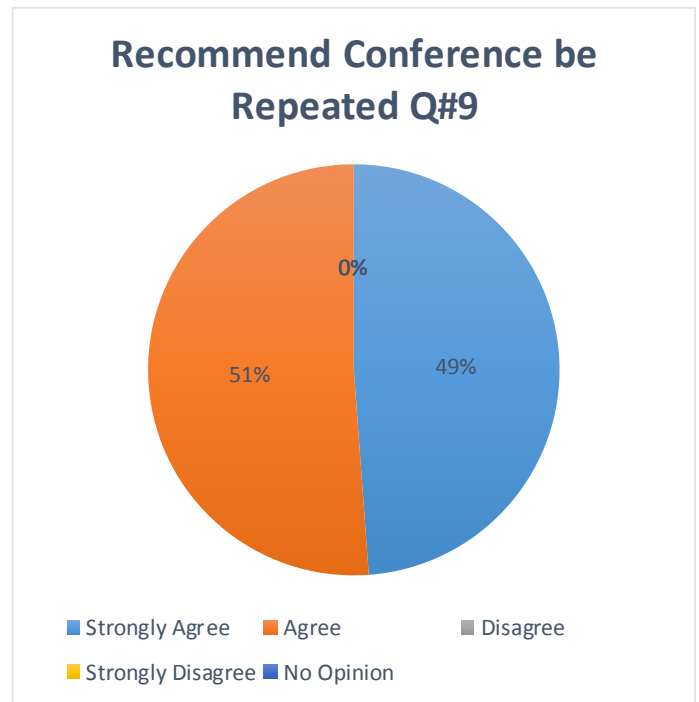


Figure III: Pie Chart showing Participants Recommendation for Conference to be Repeated



Attendees were also very satisfied with all presentations held in the Seminar (Q#1-Q#5). They found that the presenters had a good understanding of the topics. (Q#5)

Attendees also agreed and strongly agreed that the content was helpful, the level of the conference was appropriate, the format was enjoyable, were satisfied with the facilities and location of the venue, the length of the seminar was appropriate and recommended that the Conference be repeated.

IV. CONCLUSION

One of the main outcomes of the conference was the "Cancer Survivorship Guide" Towards Improving the Quality of Life of Cancer Survivors" booklet. The booklet was officially launched at the Conference and was the first of its kind in the region specifically for cancer patients in Trinidad and Tobago. The expected impact is that the booklet would be used as a resource for survivors and would be a model for use in the region. The booklet was sponsored by First Citizens Bank.

In summary, the objectives of this Conference were met as attendees were able to understand the importance of survivorship, and the delivery of care to cancer patients; since it contributes to enhancing the quality of lives of survivors throughout their cancer care continuum. It provided a forum to

discuss strategies and solutions to reduce the burden of cancer both on the patient and our communities.

APPENDIX

Appendix I: Program Schedule for the Conference.

Appendix II: Conference Evaluation Form

REFERENCES

- [1] Pan American Health Organization. (2013). Cancer in the Americas: Country Profiles 2013. Washington, D.C.
- [2] American Cancer Society, the International Agency for Research on Cancer, and the Union for International Cancer Control. (2017, November 14). *The Burden: Cancer in the Latin America and the Caribbean*. Retrieved from The Cancer Atlas: <http://canceratlas.cancer.org/the-burden/cancer-in-latin-america-and-caribbean/>
- [3] LeDuc Media (Data Sources: WHO (2014), World Bank, UNESCO, CIA and individual country databases). (n.d.). *World Health Rankings*. Retrieved November 13, 2017, from World Life Expectancy: <http://www.worldlifeexpectancy.com/country-health-profile/trinidad-tobago>
- [4] Division of Programme of Action for Cancer Therapy · International Atomic Energy Agency. (n.d.). PACT: Together against cancer. Austria: PACT Programme Office · International Atomic Energy Agency.
- [5] American Cancer Society Inc. (2016). *Cancer Treatment & Survivorship Facts & Figures 2016-2017*. Atlanta: American Cancer Society.
- [6] The Lancet Oncology Commission. (2015). Progress and remaining challenges for cancer control in Latin America and the Caribbean. *The Lancet Oncology*, 1405–1438.
- [7] Institute of Medicine and National Research Council. (2006). *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, D.C.: The National Academies Press.

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