

To: AORTIC Board

Dr. Ahmed Elzawawy, President

Dr. Lynn Denny, Exec Director

Tim Rebbeck, PhD, Coordinator of Research and Education

Dr. Folakemi Odedina, Cancer Plan for AORTIC

IPOS Board

Dr. Maggie Watson and Dr. David Kissane, Education/
Academy Committee

Elliott Graham, Exec Director

Open Society Institute

Kathy Foley, Director

Mary Callaway, Coordinator

RE: Report on the IPOS/AORTIC ACADEMY, November 20, 2013, at
Durban, South Africa

FROM: Jimmie Holland, MD, Chair

CoChairs: Chioma Asuzu, PhD and Mark Lazenby, PhD

DATE: December 8, 2013

The theme of the IPOS/AORTIC Academy was “Treating the Whole Patient: Moving Psycho-Oncology Forward”. This topic related well to theme of the AORTIC meeting which was: “Cancer in Africa: Bridging Science and Humanity”. The plenary speaker on the AORTIC program was Dr. Lois Ramondetta from MD Anderson, who spoke about “Placing the Patient’s Humanity at the Center of our Care”. The program planning for the IPOS/AORTIC Academy, was done by Dr. Holland with the critical assistance of the CoChairs who have directed research in Africa and know the key issues: Dr. Asuzu who has passionately begun research and training in Africa, beginning in Nigeria, and Dr. Lazenby,

from Yale University, who has studied spirituality in Africa, and has helped in Botswana to bring palliative care there. The three Chairs express their gratitude for the support of the many individuals who helped in making the Academy possible. (See the Appendix for the names and email addresses of the 46 persons who attended and the 8 traveling scholars representing 5 different African countries).

Session 1 (see Appendix for Minutes of the Conference) dealt with the major problem of delay in diagnosis of patients in Africa. Dr. Joe Harford, the NCI representative in Africa over many years, pointed out that the causes are both patient and system related, but delay in diagnosis is THE major problem that prevents curative treatment options. Dr Asuzu followed to report on the NCI supported study of which she was the PI. She studied 802 patients and their traditional healers in two cities in Nigeria to explore the role of traditional healers in delay. They are often the first to be consulted about a symptom and often treat the patients until too late to receive curative treatment from western medicine. She met with them in focus groups and found them interested in becoming part of the health care system. She noted that spiritual beliefs are so strong that to try to ignore this sector would not be helpful.

Dr. Jean-Marie Dangou, WHO/Africa office, was delayed and he could not attend the Academy as planned.

Session 2 began with Dr. Vincent Odigie, breast surgeon from Zaria, Nigeria who reported a study showing that by giving his breast cancer patients his cell phone number, he improved followup and reduced their distress. Distances over poor roads are long and followup appointments are difficult to keep. The women appreciated that husbands could speak to the doctor which helped. Cells phones are cheap and are available in all villages. Dr. Beatriz Wiafe-Affai, also a breast surgeon, in Ghana, spoke of the important role of women survivors in supporting newly diagnosed women. They are becoming a significant advocacy group in Ghana. The President of Ghana joined them recently in a walkathon. Advocacy is growing and Dr. Odedina,

Nigerian in Florida, is enthusiastically building and training advocates in Africa through AORTIC. She had a simultaneous two day training program and left her meeting to talk with our group about areas of overlap and the need for collaboration between our groups.

Distance learning was presented by Drs. Fitch and McLeod who are active with the AORTIC Nursing Committee. The potential to extend their virtual learning programs in Canada will be pursued. The Psychosocial Counseling Program in Ibadan was presented by Dr. Oladapo Campbell and Dr. Chioma Asuzu. She pointed out that to begin the program, she worked without being paid. She suggested that a strong sense of altruism is necessary at the start and it is often necessary to give one's services at the beginning to show the need. Their clinic is active and it functions in conjunction with the newly developed Master's psychology training program by Dr. Asuzu. The Psycho-Oncology Society of Nigeria (POSON) has developed from this academic setting in Ibadan, led by Dr. Asuzu.

Session 3 was changed, in Dr. Dangou's absence, to observations by Dr. Scott Nichols discussing implementing new health programs in developing countries, using his experience with the US State Department. Dr. Ghosh from MDAnderson presented their global programs in which professionals in Africa might participate. Dr. Andreas Ullrich from WHO arrived too late to speak but he attended subsequent discussions.

Session 4 was designed for interaction of the group. It began with a presentation by each Scholar present who had received travel support. Four had attended the Cairo Academy and this was their second conference. The 8 were designated as Special Scholars who will continue to report about their progress every 6 months to Dr. Asuzu.

INFORMAL Meetings. While the formal Academy ended around 5PM, the decision was made that during each of the following four day lunch breaks, 1:00-2:30, we would continue our discussions. This plan resulted in 8-15 individuals sharing lunch each day. Dr. Ullrich from

WHO participated in the discussion on Thursday and gave us the WHO perspective on psychosocial issues. He shared the view that they are important in cancer care in Africa. The group became better acquainted and was better able to pin point goals and identify the steps needed to reach them.

Goals were identified in two areas:

FIRST GOAL: to enhance the visibility and participation of Psycho-Oncology in the AORTIC structure. Dr. Holland will work on this by 1) requesting of President Alzawawy to appoint a Working Group status for psycho-oncology, to examine the psychological and social issues in cancer in Africa, which extend from prevention, early detection, treatment to palliative care. 2) To request of Dr. Rebbeck and Dr. Odedina to place Dr. Asuzu on the AORTIC Education and Research Committees; 3) to add Dr. Asuzu to the Young Leaders Council to represent psychological areas. 4) To request a formal session in the 2015 International Conference, in addition to the Academy.

SECOND GOAL: to work outside AORTIC, with Dr. Asuzu taking the lead role, to develop the Association for Psycho-Oncology in Africa (APOA), using the critical mass of young people who attended the AORTIC/IPOS Academy. She will work on a constitution and on representation from as many African countries as possible. By the time of the spring meeting in Ibadan, sponsored by IPOS, she will be able to propose the new society for membership in the Federation.

A number of specific recommendations were made of ways to support the clinical work and research of several Scholars: Dr. Ekortarh, psychologist in Cameroon who is working in a new site; assistance to Fadipe Babatunde, psychiatrist in Lagos in his study of depression; mentoring of Philip Odiyo in his dissertation on spirituality in cancer care in Africa.

As part of these developments, collaboration with the African Palliative Care Association is important with the goal of developing a greater role for psychosocial issues in palliative care, as well as with the

Palliative Care group in AORTIC under DR. Merriman. And to collaborate with the Advocacy Movement that is taking hold in Africa, through collaboration with Dr. Odedina in AORTIC and Dr. Wiafi-Addai in Ghana.

The overall outcome of the Academy and the four followup sessions was a collective sense that, for the first time, there is a critical mass of professionals in Africa who have the potential to take the work in Africa forward. The effort will be organized through Dr. Asuzu's office in Ibadan with the help of the psycho-oncology group there. Dr. Holland's office will work to enhance the visibility of the psycho-oncology group within AORTIC.

Report by Jimmie Holland, MD.

Minutes prepared by Drs. Asuzu and Lazenby.



AORTIC INTERNATIONAL CANCER CONFERENCE

CANCER IN AFRICA:
BRIDGING SCIENCE
AND HUMANITY

21 – 24 NOVEMBER 2013
DURBAN, SOUTH AFRICA

CONFERENCE HANDBOOK



Chairs: Drs. Holland, Asuzu and Lazenby (left to right)



Faculty Scholars and Attendees of the IPOS/AORTIC Academy



Scholars funded to attend with Drs. Asuzu and Holland



Dr. Jimmie Holland, Dr. Jean-Marie Dangor, WHO/Africa and Dr. Chioma Asuzu



Dr. Chioma Asuzu, Dr. Jimmie Holland, Dr. Andreas Ullrich, WHO/Geneva and Dr. Scott Nichols

Minutes

The African Organization for Research and Training in Cancer-International Psycho-Oncology Society Academy

L'Organisation africaine pour la recherche et l'enseignement sur le cancer-Société internationale pour la psycho-oncologie-académie

The International Conference Centre
Durban, South Africa
Wednesday 20 November 2013

1. Call to order.

Dr. Jimmie C. Holland, the Wayne E. Chapman Chair in Psycho-Oncology at Memorial Sloan-Kettering Cancer Center, called the Academy to order at 09:00. Dr. Holland's co-chairs, Drs. Chioma Asuzu, Senior Lecturer in Psycho-Oncology at the University of Ibadan, Lagos, Nigeria, and J. Mark Lazenby, Associate Professor of Nursing & Divinity and Core Faculty in the Councils of Middle East and African Studies at Yale University, New Haven, Connecticut, USA, were present with her in the call-to-order.

2. Attendance.

In attendance at the Academy were: (46 participants list attached)

3. Sessions

The Academy's first session, chaired by Dr. Scott Nichols of Chico, California, USA, focused on the psychosocial and spiritual factors in delayed diagnosis of cancer in Africa. Dr. Joe Harford, of the National Cancer Institute, Bethesda, Maryland, USA, presented a review of the scientific literature on delay of diagnosis. From this review, he brought the Academy's attention to the doubled nature of delayed diagnosis: patients' late presentation to health care providers and system delays. This doubled nature creates a total delay, that is, the time that elapses between when a patient notices symptoms of cancer and when that patient first receives treatment. Dr. Harford described reasons for both patient- and system-delays. Following Dr. Harford, Dr. Chioma Asuzu presented on her research on the spiritual factors involved in cancer care delay in a two-site study in Nigeria. Of 802 patients interviewed between the two sites, 29.5% in one site and 37.6% in another site had consulted alternative/spiritual healers before presentation to a health care provider to address concerns regarding symptoms of cancer. In a parallel arm of her study, Dr. Asuzu interviewed alternative/spiritual healers who, she found,

want to be included in the delivery of biomedical cancer care. She concluded that psycho-oncology needs to be the catalyzing agent in the multidisciplinary cancer care team through which alternative/spiritual healers are integrated into care of the whole patient. If psycho-oncology is the agent through which care of the whole patient is achieved, Dr. Asuzu argued that, for many Africans, the whole patient includes their spiritual beliefs and practices; and so, the alternative/spiritual healers whom Africans seek healing from need to be included in patients' overall cancer care.

The second session, entitled "Education and communication to improve care." This session featured four presentations. Dr. Vincent Odigie, Professor at the University of Ibadan, Nigeria, and breast cancer surgeon, presented on his study on improving doctor-patient communication through the use of mobile phones. In this study, breast cancer surgeons gave their mobile numbers to consenting patients seen for breast cancer. Six-hundred fifteen patients were instructed that they could call the consultant breast surgeons at any time of day or night to discuss concerns or troubling symptoms. Over 86% of participants rated phone use very useful, obtained information, and were not lost to follow-up by keeping or calling to reschedule appointments. Three of four women married noted that oncologists speaking with their husbands facilitated follow-up. Drs. Margaret Fitch and Deborah McLeod, both of Canada, presented on the use of distance modalities and the role of interprofessional education in teaching and learning patient- and family-centered care. Dr. Beatrice Wiage-Addai, a breast cancer surgeon from Ghana, described her work on providing psychological supports for patients with breast cancer using breast cancer survivors as lay educators and support group facilitators. Dr. Wiage-Addai also described using nurses who were themselves breast cancer survivors in the role of a breast cancer nurse, educating patients on care and follow-up.

Professor O. Campbell and Dr. Chioma Asuzu, both of the Department of Radiotherapy in the University of Ibadan, Nigeria, discussed an evolving multi-staged model for psychosocial services and training of psycho-oncologists in their department. Prof. Campbell laid the foundation for the presentation by giving a brief history of how the counseling of cancer patients began before it evolved into the psycho-oncology unit in the University College Hospital Ibadan, Nigeria. Dr. Asuzu talked on the Ibadan approach to psychosocial services highlighting the components of the Altruistic Psychosocial Model.

Professor Campbell and Dr. Asuzu concluded that this model of multidisciplinary, affordable and accessible psychosocial services as part of comprehensive cancer care for

patients and their families could help integrate psycho-oncology into routine cancer care in oncology centers throughout Africa.

The third and final session, “Routes to Change through Collaboration,” featured two speakers from the United States. Prof. Folakemi Odedina, of the University of Florida, discussed the role of patient advocates in enhancing care of the whole patient. Dr. Ghosh, of the M.D. Anderson Cancer Center of the University of Texas, informed attendees on M.D. Anderson’s global initiatives.

4. Bursaries.

NAMES AND PLACES OF BURSARY RECIPIENTS

Ekortarh Anncommy - Cameroun

Akin-Odanye Elizabeth - Nigeria

Dr. Zipporah Ali - Kenya

Ms Sokhna Ndiaye - Senegal

Dr. Fadipe Babatunde - Nigeria

Kaimukilwa Diocles - Tanzania (Absent)

Tshirelesto Molefe – Botswana

Philip Owua - Kenya (joined on the 21/11/2013)

Reports from the scholarship awardees from different African countries

EKORTARH ANNCOMMY from Cameroun

She reported that the Dean Faculty of Medicine who is a radiotherapist invited her to spend 6days a month in Douala to provide psychosocial services for cancer patients. This implies that the importance of psychosocial services to cancer patients is gradually being recognized. She also teaches medical psychology to medical students in which palliative and psychosocial care is taught to the 6th year medical students who are preparing to commence their research. She believes to move psychosocial service for cancer patients forward it is important to get the administrative heads educated on the benefits of the services.

Akin-Odanye Elizabeth from Nigeria

She reported that the Psycho-Oncology Society of Nigeria have had her third national conference and workshop. The society was able to take the workshop out of Ibadan to Benin City in the South-eastern part of the country. The essence of the workshop was to build psycho-oncology teams in each of the geopolitical zones in the country and later expand it to include as many states as possible as manpower capacity increases. The co-operation of the Chief Medical Director of the University of Benin Teaching Hospital as well as that of the HOD Department of Radiotherapy made it possible to hold the workshop in Benin hence creating an enabling environment to educate all members of staff working directly or remotely with oncology patients about the need to address psychosocial issues in cancer patients or make appropriate referral as the need arises.

Zippora Ali – Kenya

There is no unit specifically concerned with psycho-oncology however she reported that efforts are being made to integrate psychosocial service into palliative care. The hospital has a good relationship with the new cabinet secretary which implies they have political goodwill. Due to their cancer advocacy efforts, there is much interest in palliative care in the country. This year (2013) they have developed and launched several documents in conjunction with other significant bodies. Some of the documents are: The National Palliative Care Guidelines; National Palliative Care Training Curriculum; develop Diploma in Palliative Care for nurses and medical students. They also work with a psychiatrist in the hospice. They encourage other doctors to be involved in palliative. She noted that though palliative care cuts across different diseases, much emphasis is given to cancer and its psychosocial issues in the Cancer Management Guidelines.

Fadipe Babatunde – Nigeria

His first contact with psycho-oncology was at AORTIC 2011. At the time he was a resident doctor at the Neuropsychiatric Hospital in Abeokuta, Ogun State. His contact with cancer patients comes from the liaison his hospital has with a nearby Catholic hospital. His interest in psycho-oncology informed his decision to move to Lagos University Teaching Hospital in March 2012 to enable him have greater access to cancer patients. Being a resident doctor, he is not able to influence policy decisions but he is working with a psychiatrist who is interested in the psychosocial issues in cancer patients. Together they have carried out a study in which they found a prevalence of depression among 49% of cancer patients. The next step for them is to establish collaboration with the oncology department so that more research can be conducted to

provide enough evidence to convince the hospital management to consider giving greater attention to psychosocial issues in cancer patients.

Sokhna Ndiaye – Senegal

She works in the pediatric unit of her hospital. A program was set up three years ago to do individual and group counseling for children, their families and members of staff. On the unit on a regular basis she is the only one available but she works with an art therapist, pediatric psychologist and a family therapist during the therapeutic sessions hence allowing different interactive media with the different groups. They use drawing, musical therapy, photo language, psychodrama etc in counseling.

Tshirelesto Molefe – Botswana

She is an oncology nurse working in the chemotherapy department of a private hospital but they also see patients from government hospitals on referral. She hasn't done much since this is her first time however she recognizes that there is a need for collaboration with the government to see that patients are helped as there is still a lot to be done. Her clinic however often refers patients to a clinical psychologist in another centre anytime the patients are in need of such services.

Apart from the above six, the chair person, Jimmie Holland called on other participants from other countries or centers to share their experiences.

Linda Gieef (South Africa)

In the private clinic where this participant works, distress screening is done to identify patients at risk of distress as a routine. They have obtained the license to screen for distress from NCCN. This however is not the case in government hospitals as there are problems with access to care as well as inadequate infrastructure. Also there is no national cancer plan and cancer registry yet. However, there is now a better cancer alliance between the counties in which they work together in terms of advocacy. With psycho-oncology, social workers are appointed to provide psychosocial service and most state hospitals have social workers but they are often over stretched as 1 social worker often serves patients in about 10wards. South Africa also has a toll free cancer helpline.

Irene Chidothe from Malawi

Reported that they had only two oncologists in the country and on a regular day they see more than 50 patients which makes it difficult to concentrate on anything else. There is however a palliative care unit. What is being done by the oncologist is to

develop a collaboration with Dana Farber in training two nurses to provide social works services to help provide psychosocial services.

Lynette Palmer from Sierra Leone

Lynette reported that they neither had oncology unit nor oncologist in the country. She is representing a clinic that does breast cancer advocacy and research. The clinic has a counselor who counsels after diagnosis. Other centers are encouraged to send patients who have been diagnosed to attend patient and family members counseling. They encourage people to screen and sometimes get survivors to talk with the patients.

Participants were encouraged to seek out people with like minds to work with. It was acknowledged that though starting something new is not easy, participants should forge ahead with an altruistic and compassionate spirit to achieve the goal of helping cancer patients with their psychosocial issues. Participants were also informed that they will be called upon from time to time to give an account of their efforts towards establishing psycho-oncology in their various centers. It was agreed that all should meet in the hotel patio during lunch tomorrow for follow up discussions.

Respectfully noted,

Drs. Chioma Asuzu and Mark Lazenby