### Volume 1

Issues in High-, Medium-, and Low-Resource Countries

## INCIDENCE, CARE, AND EXPERIENCE

Kenneth D. Miller, MD, and Miklos Simon, MD, Editors Foreword by Sandra M. Swain

# Global Perspectives on Cancer Incidence, Care, and Experience

Volume 1: Issues in High-, Medium-, and Low-Resource Countries

> Kenneth D. Miller, MD, and Miklos Simon, MD, Editors

> Foreword by Sandra M. Swain



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### Psycho-oncology in Low-Resource Countries: Nigeria as an Example

Chioma C. Asuzu and Jimmie C. Holland

#### INTRODUCTION

Psycho-oncology is a relatively young area in the broad field of health and welfare services. Yet in many of the technologically advanced countries such as the United States, Canada, Australia, and the United Kingdom, it has become well established. These advanced countries have developed standards for psychosocial practice and quality care which led to the inclusion of distress as a sixth vital sign. However, the situation in the low-resource (middle and low-income) societies of the world is far different from that in developed countries. Most developing countries face major problems with infectious diseases, which have remained the center of medical attention, for example, malaria, respiratory and diarrheal diseases. However, with rapid westernization, diseases of lifestyle such as hypertension, diabetes, and obesity are also assuming epidemic proportions in Africa. Diet and lifestyle changes are leading to the increase of these diseases in Africa.

### PREVALENCE OF CANCER

The incidence of cancer is increasing annually, both globally and in Africa. Approximately 50% of cancer mortality occurs in developing countries—3,500,000 people/year.<sup>1,3</sup> Furthermore, it is estimated that by 2020, approximately 60% to 70% of new cases of cancer will occur in the developing world.<sup>4</sup> Cancer incidence is high globally, and Africa and Nigeria are not left out.<sup>4</sup> The African continent is expected to account for more than 1 million new cancer cases every year.<sup>5</sup> Twelve million new cases were detected globally in 2007.<sup>6</sup> By 2030, it is projected that there will be 26 million new cancer cases and 17 million cancer deaths per year.<sup>7</sup> Cancer is now the

third leading cause of death, with over 7.6 million cancer deaths estimated to have occurred globally in 2007.<sup>7</sup>

Many of the African countries experience their own unique sets of problems in relation with cancer care. In Nigeria, according to Solanke,<sup>3</sup> about 100,000 new cases of cancer occur every year, and it is expected that by the turn of the century 500,000 new cases will occur annually. Cancer is a growing problem in Nigeria<sup>2</sup> and has been observed to have devastating and frightening effects on the patient and family. Cancer mortality rate in Nigeria is highest for breast cancer, followed by cervical and prostate cancers.<sup>8</sup> This has implications for the type of physical facilities and psychological resources needed. Cancer evokes a range of emotions such as fear, anger, sadness, hopelessness, anxiety, and depression. Psychological support can therefore be critical in assuring adherence to treatment. Abrams and Finesinger have noted that cancer presents a number of demands on the individual and his or her family, which have psychological, social, and spiritual consequences.<sup>10</sup> Families that have cancer patients incur considerable expenses during and after the course of treatment. Some of these patients face additional challenges and burdens, including poor social support, family disorganization, and discord.

In the face of all the above, rising incidence of cancers and the accompanying emotional distress arising from the diagnosis and treatment, it is important that psycho-oncological services are provided in these low-resource countries in spite of all the odds and adequate support. In Nigeria, for example, at the University College Hospital, the need for psycho-oncological services was identified in 1992 by a psychiatrist, a radio-oncologist, and a gynecologist. The skeletal services started could not be sustained until 2004 when a clinical psychologist began to develop psycho-oncological care at the center. The psycho-oncological team comprises psychologists, nurses, radio-oncologists, psychiatrists, and social workers working together.

With the formation of the Psycho-Oncology Society of Nigeria (POSON) in 2009, there is now an organized group effort to help expand this development. The objectives of the society include the following: provide psychosocial treatment to cancer patients and their caregivers, provide training ground to further the work of psycho-oncology in Nigeria, create community awareness in the area of psycho-oncology in Nigeria, develop guidelines for the practice of psycho-oncology in Nigeria, conduct research in the area of psycho-oncology, act as the patient's advocate and raise funds for research, and assist patients when necessary. Six other psycho-oncology centers are similarly developing in the country. Since inception, three annual workshops and conferences have been organized. In a similar vein, the need for palliative care for many terminally ill patients was also identified, and the Centre for Palliative Care, Nigeria, was established in 2005 at the same hospital in Ibadan.

### BARRIERS TO PSYCHO-ONCOLOGICAL CARE IN NIGERIA

The problems of increasing poverty among the masses because of inadequacies of political will, political administration, and leadership constitute the most intractable problems of overall health care. These political problems contribute to immediate barriers, such as the lack of awareness about psycho-oncological care in the country, insufficient funding, and professionals necessary to provide holistic care.

Poverty, poor physical accessibility of the health services, breakdown of machines for therapy, ignorance/illiteracy, and inappropriate recourse to religion in the face of these realities all contribute to the barriers to establishing and proper functioning of psycho-oncological services in Nigeria. Negative cultural practices, ignorance, and the high cost of hospital care are other major barriers to effective treatment. The poor attitude of the medical/health staff toward cancer patients who already experience a sense of hopelessness and inevitable death is a continuing problem. Most centers do not have a structure to provide adequate chaplaincy services for the spiritual needs of these patients.

These existing barriers in the health-care system contribute to cancer patients to seek help from the traditional and alternative healers alone or alongside Western care. We have observed that very often patients are unwilling to disclose this to their physicians. These traditional healers are also unwilling to disclose or align their services with the formal psycho-oncological services because of existing suspicions between health workers and traditional healers.

During focused group discussions carried out under a pilot study of patients with cancer and their traditional healers sponsored by the African Organization for Research and Training in Cancer (AORTIC)/National Cancer Institute, some of the reasons given by patients for using the alternative healers include the following: traditional healers are readily accessible; they are not expensive, and most of the healers allow the patients to pay as and when they have the money; they have a more positive and hopeful attitude and promise cure, especially those based on faith healing. Many healers are willing to relate with the spiritual dimension to their care, which is often in keeping with the patients' beliefs.

The preceding barriers mentioned are the current challenges faced by both patients and health workers, and these challenges impact the psycho-oncological care of patients. There is an urgent need to address the problems that prevent patients from accessing health care and also the need to establish a process of working with traditional healers in a way that benefits the patient. In addition, it is important to address the structural roadblocks that prevent the incorporation of psycho-oncological services in the continuum of care. Finally, the need for increased political will, policy making, and implementation cannot be overemphasized.

### OPPORTUNITIES FOR THE GROWTH OF PSYCHO-ONCOLOGY IN NIGERIA

Apart from the improvement of the quality of life of these patients, those alternative and traditional healers that we have engaged in focus group discussion have indicated interest in working with Western health services. The opportunity to expand this cooperation will mean that such healers may be able to refer those patients to us early for diagnosis when the cancers may still be in situ and therefore curable, without our interfering with their continuing care by the alternative caregivers. One sure effect of this will be a growing number of cancer survivors whose experience, testimonies, and information dissemination individually or as an organized group will enhance wider knowledge and encourage cancer screening and early diagnosis. The effect of this in enhancing the cooperation of the Western and traditional or alternative healers in psycho-oncological care will be great. Cancer screening promotion such as health worker–assisted breast examination, Pap smear or other screening for cervical cancer, and prostate-specific antigen screening can expand and be available to the patients at minimal cost.

The opportunities also provide openings for international participation in promoting psycho-oncology. The opportunities include sponsored postgraduate training for low-resource country professionals interested in returning to advance these services, improved funding support for local research for the advancement of these services, and infrastructural support to minimize the breakdown and loss of services such as with radio-therapeutic machines in these centers. In addition, undergraduate and postgraduate students find psychological services very interesting and are often delighted to see positive changes that they could bring to these clients lives by the services.

One major area and opportunity for international participation in psycho-oncological services in resource-poor countries is the funding of local-regional exchange programs—as in the many North-South-South or Global Health Networks. In this area, the development of closer links and cooperation between the broad range of psycho-oncological services along the cancer care continuum will be very important. Cancer advocacy organizations comprising cancer survivors who want to help are beginning to develop informal support services.

The support of the International Psycho-Oncology Society (IPOS) in psycho-oncological research and staff development is important at the University of Ibadan and University College Hospital, Ibadan. The psychosocial services developed can serve as a model for other countries. With a growing number of psycho-oncologists in Nigeria, policies and standards of care for clinical psychology will be developed and applied in all the hospitals in Nigeria.

POSON is looking forward to collaborating with the existing oncology groups in the country in order to present one front to the government, that oncology care should become holistic; psycho-oncological care should be included as part of the care for all oncology patients in Nigeria, as is practiced in some of the advanced countries of the world. IPOS has developed international standards of quality care that all countries should endorse, thereby offering the framework for providing psychosocial care globally to anyone who is living or affected by cancer, both young and old.

The efforts to develop psychosocial services have been overshadowed by the need for palliative care because people in Africa come in too late for treatment—curative treatment. AORTIC, over 20 years old, has included attention to the psychosocial services in the context of its education in palliative care. The Pan-African Palliative care Association is increasingly strong in providing pain management and educating about the importance of end-of-life care. Through the existing hospice organization, AORTIC, in collaboration with IPOS, strives to develop a network of psychologists, nurses, and physicians who will be able to advocate for psychosocial services and for education of medical learning about the importance of attitude and communication with patients. The importance of empathy and understanding while delivering care is critical for all. Uncaring or negative attitudes of the doctor or nurse are painful for ill and frightened patients. Attention to psychosocial aspects of care can significantly improve the outcome of patients.

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