

The Delivery of Psychosocial Services in an Oncology Setting: The Ibadan Experience

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Abstract

The diagnosis of cancer and its treatment have serious multiple impacts on the different domains of the patients' lives as well as that of their caregivers. It is often challenging for patients to cope effectively with the social, emotional, spiritual and physical impact of the disease without psychosocial support. Psychosocial health services refer to those psychological and social services as well as interventions provided to patients to enable them, their families, and health care providers get the best possible care from the health care system and to manage the psychological, social/cultural and behavioral aspects of illness and its consequences so as to enhance quality of life. These psychosocial services include, but are not limited to distress screening and management through psychological interventions, group and individual counselling, nutritional counselling, psycho-education services, provisions of breast prostheses free of charge or at minimal cost etc. While giving psychosocial services to cancer patients in most of North America and Europe is almost the norm today, much is still left to be done to accomplish this in Nigeria. This paper gives an insight into what has been done so far in Nigeria to ensure that the provision of psychosocial services in oncology setting becomes part of standard care.

Keywords: Cancer; Psychosocial service; Psycho-Oncology; Ibadan; Nigeria

Introduction

Cancer is a chronic physical disease, with far reaching consequences for the psychological, social, functional and spiritual wellbeing of those whose lives are affected. The diagnosis of cancer is often complicated by the accompanied experience of depression, anxiety and emotional distress as well as other psychosocial challenges which may emerge at any point along the cancer care continuum. High levels of emotional distress have been reported in about a-third of people living with one cancer or the other in outpatient settings with this incidence almost doubling among inpatients [1,2]. The invaluable role of distress screening and intervention in controlling the extent of cancer-related distress resulting in enhanced mental and psychological coping as well as enhanced quality of life has been well established in literature [3-6].

The International Psycho-oncology Society (IPOS) has continued to reiterate the importance of ensuring quality cancer care through integrating psychosocial domain into routine care and by measuring distress as the 6th vital sign after temperature, pulse, respiratory rate, blood pressure and pain [7]. This means that as other vital signs are being assessed, distress should be assessed along; especially in oncology settings. Moreover, the National Comprehensive Cancer Network (NCCN) standards for distress management state that: "all patients should be screened to ascertain their level of distress at the initial visit, at appropriate intervals and as clinically indicated, especially when changes occur in disease status (remission, recurrence or progression) [8]. For the screening services to be worth the effort however, there is a need to follow it up with appropriate assessment, intervention and follow up to ensure that identified and diagnosed distress is relieved and treatment effect sustained.

This article describes the dynamics of delivering psychosocial services in an oncology setting in a developing country, Nigeria. It gives a brief history of how the delivery of psychosocial services to cancer patients started in Ibadan, a description of the psychosocial services offered, some challenges to enshrining the practice of psychosocial screening and intervention programs into mainstream cancer care and the way forward.

History of Psycho-Oncology in Ibadan

According to Holland [9], the formal beginning of psycho-oncology in America commenced with the progressive positive change of attitude and behaviour towards the concept of cancer in the mid-1970s. In Nigeria, the history of psycho-oncology could be traced to the desire of three medical doctors (a radiation oncologist, a psychiatrist and a gynecologist) to equip cancer patients with knowledge about their disease, while assessing and addressing their emotional problems with the aim of reducing their fears and enhancing their quality of life. This desire led to the establishment of Lola Marinho Cancer Counselling Centre in 1992. The effort of the medical doctors however did not get the needed and sustained services of a counselling or clinical psychologist until 2004 when the present sustained services of clinical psychologist became available. This rather humble beginning marked by six years of sustained psycho-oncology services set the stage for the establishment of the Psycho-oncology Unit in the Department of Radiotherapy, University College Hospital, Ibadan in 2010.

Psychosocial Services Offered in the Psycho-Oncology Unit

This narrative is focused on the dynamics of the Psycho-oncology unit in the Department of Radiotherapy, University College Hospital,

Ibadan as it relates to the psychosocial services offered to oncology patients and their caregivers. The adjunct care provided for cancer patients through this unit is not focused on the disease itself but rather on addressing the negative emotional, social and spiritual impact of the disease on the person with cancer and their caregivers. Different modalities are adopted in helping patients to access psychosocial care. These are the every Tuesday psycho-education sessions, ward rounds and also through physician-referral or self-referral by the patients.

The every Tuesday psycho-education session is run by a multidisciplinary team made up of clinical psychologists, counselors, oncology nurses, resident doctors, social workers, public health nurses, dietician and students on practicum. The team at every session is led by a clinical psychologist. Other members of the team have attended psycho-oncology workshops (either local or international) to acquire the skills needed to provide psychosocial care.

A typical Tuesday session starts at 9 am and ends at 10 am after which the normal clinic for the day begins. Getting patients to attend the Tuesday sessions is not difficult as all patients are officially expected to attend the sessions. However, patients are not forced against their will to attend. Patients are sometimes reluctant to attend the sessions due to annoyance that the radiotherapy machine is down or not seeing the connection between attending a psycho-education session and the treatment they have come for. Each session is begun by clarifying the purpose of the session and informing patients and their caregiver that the psycho-oncology unit is available to help them deal with whatever psychosocial distress they may be encountering as a result of cancer.

Each month, a topic from the most prevalent cancer types seen in the hospital is discussed every week so that every patient receiving treatment in the clinic that month will have access to the information. This is done due to the result of a need assessment study indicating that patients were interested in knowing about the causes of cancer and the early signs of the disease as well as issues related to their diet [10]. In discussing the different topics, the psychosocial impact of the disease and the side effects of the different treatment modalities as well as how to cope is strongly emphasized.

Patients and their caregivers were given opportunities to ask questions, share personal cancer experiences or concerns about treatment outcome. The members of the team and the patients and/or their caregivers sometimes pick on a particular topic or aspect of a shared experience for more in-depth discussion. There are occasions when cancer survivors on annual appointments are invited to share the testimony of their cancer remission with the group. This serves the purpose of creating hope and the will to live in patients while also helping them develop a more optimistic attitude to the disease and the treatment they are receiving.

The session is normally concluded with a breathing exercise. It often takes the form of mindfully breathing in and out with eyes closed. The breathing in is accompanied with the thought 'I am breathing in life, health, peace and strength' while the breathing out is accompanied with the thought 'I am breathing out pains, stress, worries and anxiety'. The breathing exercise could be done with guided imagery using patients' preferred peaceful scene, positive self-statement, mentally recalling emotions linked with pleasant past experiences and the imagination of light effortlessly replacing darkness. Patients are informed of the availability of chaplaincy services in the hospital and that they have opportunities to ask for individual as well as family counseling services.

An average of 20 patients attend the sessions weekly when the radiotherapy machine is functioning well with about four patients/caregivers staying behind to see the clinical psychologist on a one-to-one basis. Recurring cases for individual counseling are anxiety over disease progression especially in relation to inadequate power supply and breakdown of the radiotherapy machine; sexuality problems especially in relation to the healthy spouse (mostly male) demanding for sex when the patient is least interested in it and problems associated with fear of death and feelings of worthlessness. Problems relating to where to stay while receiving treatment also come up from patients coming for treatment from outside Ibadan town. Such patients are referred to the social workers to be allocated a place at the Alaanu House.

During ward rounds, patients suspected of being distressed are engaged in further therapeutic discussion and administered the NCCN Distress Thermometer in order to diagnose the cause of the distress and decide on the most appropriate approach to manage the patient psychologically. Sometimes also, physicians refer patients with suspected cases of depression and psychosomatic complaints to the psycho-oncologists.

In order for more patients to access psychosocial services, oncology nurses in the department are trained in-house to assess distress using the distress thermometer. Nurses are often the patients' first point of contact and they often come into more contact with the patients than any other member of the healthcare profession. Distressed patients are most likely to be first noticed by nurses. If nurses trained in psychosocial care of cancer patients are able to detect distress in patients, then they are able to give timely intervention and when the presenting condition is beyond their expertise, they refer the patient to the clinical psychologist. Similar approach has been used in low and medium income countries where mental health personnel are not readily available [11-13].

There are studies of the positive impact of psycho-educational interventions in reducing distress in cancer patients from low and medium income countries [14,15] but only very few studies described the provision of ongoing formal psychosocial care for cancer patients within their setting [16,17]. It has however been observed that giving psychosocial services demand that much time be spent with a patient which is often tasking given the busy nature of out-patient clinics hence the need to consider the use of clinical psychologists, oncology nurses and cancer survivor volunteers as part of cancer patients management team as obtains in more developed countries [18].

The Tuesday psycho-education session is not taught as an intervention *per se* but rather as a medium whereby psychosocial problems can be prevented and those with psychosocial problems can be detected early, managed and awareness created for psychological services. This psycho-education provides the patients opportunity to ask questions, received clarifications and be informed. An in-depth interview with four of the patients (three females and a male) who had attended the sessions showed that patients found the sessions useful. Areas where the patients found the sessions most useful were related to information about the nature of cancer, diet and getting to know how to cope with the side effects of radiotherapy and chemotherapy treatments. A patient learnt from the experience of other cancer survivors who come for annual check-ups. The patients believed the sessions should be handled by a multi-disciplinary team. The patients opine that the sessions should continue to give hope and let patients know that they can live again". It has been pointed out that planned psycho-educational programs assist patients and their families to cope

with and adapt to the difficulties associated with the disease, enable them to develop their problem solving skills and increase their quality of life [19,20].

The Altruistic Model of Psychosocial Care

Psychosocial care in Ibadan is based on Altruistic Model. Given the low level of awareness about psycho-oncology and the relevance of delivering psychosocial services to cancer patients and their family members, it was important to initially offer the services without demanding financial rewards but just the permission to have access to the patients and their family members on a regular basis. Similar pattern is reported at a hospice setting in a developing nation where monetary benefit was not the reason for the majority of staff serving in the organization to provide care for cancer patients [21].

While interacting with patients, it was also important to develop a professional relationship with the oncologists and nurses based on rapport. Such rapport makes it possible to discuss patients' concerns with the health care providers when necessary and for the health care providers to refer patients for psychosocial service if need be. Through an altruistic, service oriented and multidisciplinary approach the model seeks to meet the information and educational needs of three groups. The general public is educated about cancer and cancer screening services in order to reduce late presentation at oncology clinics; the cancer patients and/or their caregivers are informed about the possible link between a cancer diagnosis and psychosocial crisis as well as the availability of psychosocial services; finally, the health care providers are educated through training workshops on the need to identify patients experiencing distress and make appropriate referrals. A similar pattern of development of psychosocial services was reported in India where local seminars in psychosocial oncology for professionals in the health sector were organized [22]. The model also incorporates social/system, behavioural, cognitive and existential approaches to help patients deal with their cancer diagnosis and management.

Present Challenges and Way Forward

It has been a challenging task for the oncology nurses to persist in the administration of the distress thermometer to patients in addition to their routine clinical and administrative duties. Moreover, the distress thermometer is not incorporated into the patients' case note as there is yet to be an institutional approval for that. Hence it is impossible for an interested physician to immediately assess the information on previous levels of psychological distress in a patient. This type of situation makes it difficult to fully consider the patients' psychological wellbeing in the overall treatment plan. Also because psycho-oncology is still a relatively new program in the oncology setting in the country there is still some skepticism from physicians and hospital administrators about the relevance and place of psychosocial services in oncology settings. This is apart from well noted psychological problems of cancer patients in this hospital which necessitated this service and other published works from this same setting [6].

The University College Hospital management must be commended for being the first and best in incorporating psychosocial care into the mainstream of cancer treatment services in Nigeria. It is recommended that more fulltime staff (clinical psychologists, counselors or social workers) be employed or redeployed from other departments (and trained) solely to provide psychosocial services for

cancer patients so that the different domains of psychosocial care can be efficiently handled by specific member(s) of the psycho-oncology team. Since this service, for now, is only taking place at the Radiotherapy Department which is usually a terminal referral service for cancer, similar services are obviously needed at the more primary and first referral cancer care departments of the hospital such as Surgical, Gynaecological, Otorhinolaryngological, Pediatric and the other medical oncology clinics from which many of these patients are referred for adjunct radiotherapy treatment.

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