

# Cancer Registry in Sudan: A Brief Overview

I E Saeed, D A Abuidris, K E H.Mohamed, S I Mohammed

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## Abstract

The first national cancer registry in Sudan started in 1967 with a grant from the International Union against Cancer (IUAC). The materials were collated through the Departments of Pathology in the School of Medicine University of Khartoum and Stack Medical Research Laboratory, and Ministry of Health. However, the cancer registry was short lived and its activity was discontinued in early 1980s due to lack of funds. Therefore, the cancer burden in the Sudan is not known. However, according to hospitals reports, cancer was the third leading cause of death after malaria and viral pneumonia accounting for 5% of all death in Sudan. Recently a National Cancer Registry has been established in Sudan to develop a system that will facilitate creation and maintenance of local and regional data and assembling these data into a single central accessible system. This overview will discuss all cancer registration activities in Sudan since the early sixties. Also present challenges and future prospect of cancer registration in Sudan as a fundamental infrastructure component of a comprehensive cancer control in Sudan.

## INTRODUCTION

Sudan is located in North African region neighboring seven countries; Central African Republic, Chad, Egypt, Eritrea, Ethiopia, Libya, and South Sudan and has a coastline with the Red Sea. The new Sudan area is 695,000 square miles, the third-largest country in Africa (after having been the largest area until the July 2011 secession of South Sudan) and slightly less than a quarter the size of the continental United States. Sudan is a decentralized federal state divided into states (composed of 26 states, called wilaya) and local government [1].

Sudan population as of July 2012 estimate is about 34 million with 49% of the population living in urban areas. It is one of the most diverse on the African continent. It made of 600 ethnic and tribal subdivisions and 400 languages. Among these are several distinct tribal groups that include the Kababish of northern Kordofan (a camel-raising people); the Ja'alini and Shaigiyya groups; the semi-nomadic Baggara of Kordofan and Darfur; the Hamitic Beja in the Red Sea area and Nubians of the northern Nile areas; and Fur in the western part of the country.

Khartoum is the capital of Sudan, with its current population of about 5 million. It lies between the White and blue Niles. Khartoum, together with the two cities, Omdurman and Khartoum North constitute the National Capital of the Sudan (tri-capital). Due to continued immigration of people as

result of economic hardship and war displacement, the Khartoum population is a fair representation of the general population of the entire Sudan.

Since its independence in 1956, it has been plagued by civil war between northern and the southern Sudan. South Sudan is underdeveloped relative to the north. Although Sudan is rich in term of natural and human resources, it remains a low-income country. In term of human development, it ranked 139/177 countries and its human development index is 0.505 in 2005 [2]. Recently, Sudan economy grew due to increase in oil production and large inflow of foreign direct investment. About 80% of Sudan work force involved in Agriculture.

Sudan epidemiological profile largely dominated by communicable diseases, however, certain problems, in particular malnutrition and tropical diseases, are of a magnitude, often reaching crisis proportions [3]. In addition to the infectious disease burden, Sudan now is facing other challenges from non-communicable diseases. Cardiovascular, diabetes and cancer top the three most diseases-causing deaths in the Sudan [4]. Despite the increased prevalence of cancer in Sudan, few effective programs are available. Most patients present at advanced stage of the disease. The only available treatment is surgery or radiation therapy or palliative care. In truth of matter the effect of cancer tragedy in the Sudan is not known yet, inadequate diagnostic

facilities and trained health workers and infrastructure, all contribute to lack of cancer reporting. But increasing numbers and death from cancer has drawn the attention of both the health professional and the public. This led to establishment of some programs to understand extend of cancer problem. Among these is establishment of the National Cancer Registry. In the hope, it will provide data on incidence and prevalence of cancer in Sudan population, common cancers and their trends. This information is valuable in allowing policy makers to implement cancer control measures and prevention strategies.

### **Cancer in Sudan**

Cancer registration in Sudan is solely reliant on hospital-based cancer recoding system without knowledge of population background. Most of these systems are within the general health information system of the health institution and mostly paper based. Majority of the registration practices do not comply with the current data privacy and security policies or health data protection. Few studies from these hospital-based cancer registries reported that cancer was the third leading cause of death in Sudan hospitals after two infectious diseases, malaria and viral pneumonia. It account to 5% of all deaths while malaria and viral pneumonia contribute 19.1% and 6.1%, respectively [5]. Earlier studies of 1334 histopathologically examined malignant tumors registered at the Stack Medical Research Laboratories during the period 1935-1954, reported that the commonest cancer were the skin (32.8%, 437/1334) followed by breast tumors (22.9%, 306/1334)[6]. However, A report from Radiation and Isotope Center in Khartoum (RICK) of 10,410 cancer cases treated between 1967 and 1984 documented that the commonest cancers in males were those of the nasopharynx and Kaposi sarcoma which accounted for 7.2% of all treated cancers [7]. In females, the commonest cancers were breast, cervix, ovary and mouth, respectively [7].

In recent years, most of the published cancer studies focused in examining one type of cancer. A study of hundred and eighty-five patients attended Ear, Nose and Throat Department of Khartoum Teaching Hospital reported hat nasopharynx cancer were more prevalent tumor with male to female ratio of 2.6:1. The disease more clustered in the towns of Dilling, Kadogli and the surrounding rural area of the Nuba Mountains [8]. Furthermore, study examined the National Cancer Institute; University of Gezira registry reported that prostate cancer was the commonest cancer among male patients treated [9]. Despite the problems

associated with interpretation of the above hospital-based cases, the information gathered provides invaluable data of cancer burden in Sudan as there is no data available in incidence and mortality.

### **Cancer Registry in Sudan**

The first National Cancer Registry (NCR) in Sudan started in 1967 with a grant from the International Union against Cancer (IUAC). However, the cancer registry was short lived and its activity was discontinued in early 1980s due to lack of funds. At that time the main sources for cancer data are the Department of Pathology in the Faculty of Medicine University of Khartoum, and Stack Medical Research Laboratory, Ministry of Health. The registry is based on histopathologically confirmed cases diagnosed at the Stack Medical Research Laboratories. Up to year 1978, the Stack Medical Research Laboratories provided histopathology services for the entire Sudan, which aided in accruing cancer database within the Center [10]. To date, the data is available at the Stack laboratories, currently known as National Health laboratories.

Another source of cancer data, is the Radiation and Isotope Center at Khartoum (RICK), Hospital based Registry. Till recently, RICK was the only center specialized in radiotherapy treatment throughout Sudan. RICK started in 1964 as small laboratory at Khartoum Specialized Teaching Hospital. In corporation with International Atomic Energy Agency, RICK was officially inaugurated in December 1966 as a separate Hospital. At its humble beginning RICK mainly treated cancers as well as diagnosed the disease using radioactive isotope, early in the 1980<sup>th</sup> the center expanded to include nuclear as well as clinical departments with all necessary cancer expertise. These expertise included treatment Clinical Radiotherapists, Medical Oncologists, and Pediatric Oncologists, Nuclear Medicine Specialists, Diagnostic Radiologists and patient's social and psychological services. The center receives referrals from all over the country. Two Senior Clinical Oncologists and 20 Junior Consultants, and one Medical Oncologist, 2 Pediatric Oncologist, operate the center. As of 2005 data the center sees about 5,000 cancer patients per year .Up to year 1999, data in the center was collected manually however, by the year 2000 computerized data collection was implemented using SPSS.

Thereafter, more additional regional histopathology laboratories were established. The first regional laboratory was established in University of Gezira in 1979. Later in

2006, the University of Gezira with the support of the International Agency for Research (IARC) established the first population-based cancer registry in the Sudan. It uses CanReg4 format. The population of the State is about 4 million, accounting to 10% of the total Sudanese population

### Sudan National Cancer Registry

Recently, in 2009 with fund from Ministry of Health a population-based National Cancer Registry (NCR) was established in Khartoum. Ministry of health's plan is to create a cancer institute in every of the 14 States within which a regional cancer registry will be established. The registry is staffed with a director and data collection and entry personnel. The NCR is charged to develop a system that will facilitate creation and maintenance of local and regional data and merging these data into a single central accessible system.

The objective of the registry are to

1. Establish and maintain good quality records of cancer cases in Sudan.
2. Enhance cancer cases registration in all health care provision levels (primary, secondary and tertiary), private clinics, and related health institutions.
3. Promote the collection of complete, accurate and timed reporting of cancer data covering initial and subsequent diagnoses, first and subsequent treatments, and follow-up.
4. Improve the quality of the registered cancer information, the storage and the reporting procedures providing the targeted institutions with extensible and customizable modular tools to integrate within their systems.
5. Help researchers in conducting research on specific cancers of importance in Sudan with regard to their epidemiology, etiology, and treatment and tie them with the operational healthcare delivery system.

### The proposed structure and methodology of work in the Sudan National Cancer Registry

The system organization originates at the community level by identifying all rural hospitals and designates each hospital as data collection center. The local service provider will transfer the suspected patients and their information to the rural hospital for complete follow up. The cases will then be classified based on diagnosis, type of cancer and stage at the rural hospital insuring data completeness to avoid a

repetition at the higher levels of registration. The data will then be transmitted monthly to the state coordinator of the NCR. At the state level, the information will be reviewed and entered in the electronic registration system. The states will transmit the cancer data to the National Cancer Registry every month.

At the federal level, the statisticians will enter the information in the electronic system, again making sure reviewing the data to avoid a repetition of the registration (duplication can be detected by CANREG5). An annual report will be prepared and distributed to hospitals, labs and treatment centers to coordinate tasks and functions.

### Procedure for reporting:

1. Hospital-employed registration officers will report hospital cases.
2. Registration officers employed by radiation therapy centers will report cancer cases.
3. Private and pathology laboratories will allow the registry officers to identify and extract the required information during routine visits to pathology laboratories.
4. In rural health centers where pathology laboratories are absent each case diagnosed clinically as tumor will be reported to the state cancer registry. All reports from the state cancer registry will be sent to the national cancer registry.

In addition, to the above reports other sources of cancer data are private sector, medical information for travelers from aboard and death certificates. Incomplete information received from the any source will be completed from diagnosis and treatment reports received from other centers such as referral pathology laboratory and radiotherapy centers.

**Data quality assurance:** Registry personnel will review the records maintained by hospitals, pathology laboratories, private clinics and physicians to assure completeness and accuracy of reported data. Likewise the collected data by the registry staff during their visits to these health facilities will be checked again before entered in the computer system to assure completeness and prevent duplication. Following the data entry, the data will be checked once more for duplication using CANREG5.

**NCR activities:** During the period 2009-2011, the NCR

began its activities by appointing staff, securing a building to house the facility, and succeeding in training 3 registrars abroad in the field of cancer registration and epidemiology (France, Egypt, South Africa, Sweden, and England). Moreover, the registry was successful in commencing its work in Khartoum State by collecting cancer data from all governmental and private health facilities and histopathology laboratories. Prior to the beginning of data abstraction and acquisition, meetings with histopathologists, oncologists, and key health workers were held. The main objectives of these meetings were to raise awareness about the importance of cancer registration and to encourage participation in this important task.

In order to have an adequate number of sources within Khartoum State, a total of 30 governmental hospitals, 14 histopathology laboratories, 74 private hospitals, medical aboard and death certificate offices were visited. Of these pathology laboratories of the major hospitals are the main source as more than 85-90% of cancer cases have microscopic diagnosis. A statistician in each of these hospitals assigned the task of a registration officer for NCR to collect data at monthly bases. A registration form designed, pretested, and endorsed by the cancer council. Registration books were prepared and distributed to private clinics for data collection. Forty-five registration officers trained for abstracting and documenting the cancer information from patient records. Upon receipt at NCR, data were reviewed for accuracy and completeness, and entered in the computer system using CANReg5. Benign cancer cases are usually excluded.

NCR staffs through quarterly visits to each state to check for data completeness, discuss problems and provide guidance conduct Monitoring and evaluation. Similar arrangements also carried at the state level.

Weakness encountered by the registry are the lack of regular budget for running cost and research activities, lack of fund for expansion of cancer registration at state level, weak health information system in cancer registration (lack of statisticians), and lack of standardized pathological reporting. Furthermore, lack of awareness of policy makers and health personnel in the importance of cancer registration and inadequate cancer research.

Challenges facing the registry currently are the need for capacity building, expansion of registration to other states, improvement of cancer registration in health information

system (training of statisticians), standardization of pathological report, establishment of cancer information networking, and publicity (published annual report).

The National Cancer registry plans are to establish a clear referral system for cancer patients and integrate it within the early detection programs, expansion of cancer registration in all other states, link with the health education units in Ministry of Health for performing health education interventions. As well as establishing training courses for the medical doctors and health workers of all categories for registration knowledge and coding and training human resources such as data management staff, registration officers, and medical registrars. In addition, NCR plan to establish information network with regional and international organization, cancer registries and database.

### CONCLUSION:

The burden of cancer in Sudan is not known. This attributed to the lack of regional and national cancer registries. The few studies that examined the hospital-based data showed that cancer is prevalent in Sudanese hospitals. This led to establishment of National Cancer Registry to facilitate creation and maintenance of local and regional data and assembling these data into a single central accessible system. By doing so it will provide data to guide comprehensive cancer control program in Sudan

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**Author Information**

**Intisar Elfadil Saeed**

Cancer Registry Center, Federal Ministry of Health  
Republic of Sudan

**Dafalla Abuidris Abuidris**

National Cancer Institute, University of Gezera  
Wadmadani, Republic of Sudan

**Kamal Eldin H.Mohamed**

Radiation and Isotopes Center Khartoum (RICK)  
Khartoum, Republic of Sudan

**Sulma I Mohammed**

Purdue University Cancer Center for Research and Comparative Pathobiology, Purdue University  
West Lafayette IN  
mohammes@purdue.edu