The Vital role of Cancer Registries in Cancer Control Program; Wake-up Call for Nigeria and Sub-Saharan Africa

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Abstract

Background: Cancer registry is an essential part of a balanced cancer control program that enables efficient planning and implementation of control program. Included as part of the resolution of World Health Assembly is a responsibility of Member States to establish population-based cancer registries. Africa particularly has sparse population-based cancer registration coverage. This paper aims to highlight cancer registries and the unique role it plays in cancer control and research, drawing attention to the need for an improved cancer registration in countries of Africa.

Methods: Relevant published literature on cancer registries in the past two decades were reviewed using different search methods.

Results: Cancer registration is essential for cancer control. It is cost-effective and assists countries of the world in setting priorities by identifying cancers with the highest burden, planning for emerging trends, focusing research where it is needed and allocating resources. Population-based cancer registries (PBCR) are the best option to measure and understand the cancer burden in the country by providing regional peculiarities and national estimates.

Conclusion: Countries in sub-Saharan Africa need a working cancer control program to help battle the ever-increasing burden of cancer. Establishing and maintaining a population-based cancer registry is feasible in all populations, even in low-resource settings, as well as improving both the quantity and quality, particularly in sub-Saharan Africa. It is critical for ensuring that cancer prevention and control interventions are making progress.

Keywords: Cancer Registries, Cancer Control Program. Wake-up Call, Nigeria, sub-Saharan Africa.
Conflicts of Interest: None declared.

Background

The cancer registry is an essential part of any balanced cancer control program. Cancer causes 1 in every 6 deaths globally, more than AIDS, tuberculosis and malaria combined.[1] It is an increasing problem in Africa and the number of new cancer cases will more than double between 2018 and 2040; faster than any other region of the world because of demographic changes.[2,3] The increase is likely to be even greater, given the ongoing urbanization of Africa, with associated changes in lifestyles.[4] Despite this growing cancer burden, cancer continues to receive a relatively low public health priority in Africa, largely because of limited resources and other pressing public health problems, including communicable diseases such as Acquired Immune Deficiency Syndrome (AIDS)/Human Immunodeficiency Virus (HIV) infection, malaria and tuberculosis.

A Cancer Registry has been defined by the National

Cancer Registry Association as an information system designed for the collection, management, and analysis of data on persons with the diagnosis of a malignant or neoplastic disease.[5] It forms the basis for national cancer control plans in all countries. Cancer registries collect cancer-related information such as: demographics, medical history, diagnosis and prognosis indicators, treatment patterns, cancer recurrence, survival rates, health care insurance coverage and patient eligibility for clinical trials. Successful Cancer Registries use healthcare analytics technology that goes beyond data collection and data warehousing, play crucial role in advancing care and research. They acquire various data using leading technology and standards, assemble the data into real-world evidence using advanced analytics and data science, enable various users to act on the evidence using various decision-making tools.[6]

There is an increasing global recognition of the need for high-level investment in the control of cancer alongside other major non-communicable diseases (NCDs). The Seventieth World Health Assembly (WHA) held on 30th May, 2017, and governments from around the world adopted a resolution in response to the growing burden of cancer. Cancer is currently responsible for one in three premature deaths globally, ranking above infectious and parasitic diseases, cardiovascular diseases, intentional and unintentional injuries.[7] To fight cancer burden, the extent of the cancer must be known to enable efficient planning and implementation of programs for cancer control. The World Health Organization (WHO) has promoted the development of national cancer control program to reduce cancer incidence and mortality and improve the quality of life of cancer patients in individual countries and states. This is accomplished through the systematic and equitable implementation of evidence-based strategies for prevention, early detection, treatment and palliation, and making the best use of available resources. The need for a functional cancer surveillance system is evident in all documents relating to cancer control planning, as is the essential role of cancer registries in the context of low- and middle-income countries. The WHA passed a resolution on cancer prevention and control. All WHO Member States especially developing countries, were called upon to intensify action against cancer by developing and reinforcing cancer control programs, developing or maintaining national cancer registry containing the type and location of the cancer and its geographical distribution.[8] Furthermore, the 2017 cancer resolution builds on the WHO Global Action Plan for the Prevention and Control of NCDs 2013–2020 and the United Nations Sustainable Development Goals 2015–2030, which include the target (SDG 3.4) to reduce premature mortality from NCDs by one third by 2030. Included as part of the resolution is a responsibility of Member States to establish population-based cancer registries to inform planning. As part of concerted fight against cancer scourge, this paper aims to highlight cancer registries and the unique role it plays in cancer control and research, drawing attention to the need for an improved cancer registration in countries of sub-Saharan Africa.

Methods

Relevant published literature on cancer registries in the past two decades were reviewed using different search methods.

Given the changing landscape of cancer burden and cancer surveillance, the International Agency for Research (IARC) established the Global Initiative for Cancer Registry Development (GICR) in 2011, as a coordinated multi-partner approach to improving the availability of the data necessary to drive policy and reduce the burden and suffering due to cancer. The GICR works through a group of Regional Hubs, which are tasked with providing expertise and support to registries in their respective regions. In 2012, the African Cancer Registry Network (AFCRN) was formally inaugurated as a consortium of registries with a defined set of membership criteria. In the same year it became the Regional Network Hub for Sub-Saharan Africa (SSA). The

AFCRN expanded the activities of its predecessor, the East African Cancer Registry Network (EARN), which was established in January 2011. The AFCRN is a project of the Cancer Registry Program of the International Network for Cancer Treatment and Research (INCTR) which aims to improve the effectiveness of cancer surveillance in sub-Saharan Africa by providing expert evaluation of current problems and technical support to remedy identified barriers, with the long-term goals of strengthening health systems and creating research platforms for the identification of problems, priorities, and targets for intervention.[9] Cancer surveillance is essential to informing governments about cancer incidence and mortality, the impact of cancer control strategies and program and, more broadly, efforts towards the realization of Universal Health Coverage (UHC). Since the adoption of the WHA resolution, the International Agency for Research on Cancer (IARC) and the Union for International Cancer Control (UICC), together with the International Cancer Control Partnership (ICCP), a group of organizations working to advance cancer control, are stepping up efforts to support the development, implementation and evaluation of national cancer control plans (NCCPs), informed by robust cancer surveillance data. The Global Initiative for Cancer Registry Development (GICR) was launched by IARC in 2011 as a partnership with UICC and other international organizations.[9,10] The overall objective of GICR is to coordinate actions to strengthen cancer surveillance data through increasing the availability and quality of population-based cancer registry (PBCR) information on the incidence, characteristics, and outcome of cancer. By doing so, GICR aids governments in obtaining the information needed to guide national cancer planning efforts, and the World Health Organization with a mechanism for supporting Member States in measuring cancer incidence as a core indicator within the Non-Communicable Disease Global Monitoring Framework.

At present, there are more than 700 cancer registries worldwide. Only about 21% of the world's population is covered by population-based cancer registries, with particularly sparse registration coverage in Asia (8% of the total population) and 11% in Africa.[12] Although, WHO reported that 60% of the 46 countries of sub-Saharan Africa (members of the African region of the World Health Organization) had population-based cancer registries in 2015,[4] in January 2019 only 24 countries had registries that met minimum criteria for completeness of cases ascertainment (> 70% of the cases expected in the area being registered), hence, qualified as members of AFCRN.[4]

Types of Cancer Registries include:

Hospital based cancer registry

A hospital registry is the monitor of the cancer program at a particular health care facility. They are primarily institution-based. All patients diagnosed or treated at the hospital are entered into the Cancer Registry database. The data are used to improve patient care by assessing patterns of care and outcomes relative to national norms. Registry data allows the hospital to measure their quality of care for continuing improvement. The data are aggregated with state and national data, and is used to educate staff and determine resource allocation.[11, 13]

Population based cancer registry

Population-based cancer registries (PBCRs) seek to collect data on all new cases of cancer occurring in a well-defined population. Usually, the population consists of the residents in a particular geographic region.[13] The main objective of population-based cancer registries is to provide statistics on the occurrence of cancer in that population and to provide a framework for assessing and controlling the impact of cancer in the community. While hospital-based and special registries may contribute data to PBCRs, they have fundamental differences in their core functions and are not a substitute for them.[14]

Specialized cancer registry

Specialized registries collect and maintain data on a particular type of cancer. An example is the Gilda Radner Familial Ovarian Cancer Registry,[15] which collects cancer information on families with ovarian cancer.

State cancer registry

State registries collect and maintain data on cancer occurring at the state level within the country.

National cancer registry

National registries collect and maintain data from the state cancer registries. Healthcare providers record patient information and diagnosis. Hospital-based cancer registrar abstracts patient information into uniform data sets and checks for an existing record for each, patient data are aggregated on a state level, and then sent to national registries (SEER or NPCR)

Core Functions of Cancer Registry

Case finding: This is the process of finding all eligible cases for inclusion in the cancer registry.

Abstracting: The process of collecting all required data elements from electronic or paper-based resources from a patient's record and converting it to uniform data.

Follow up: The process of continuous surveillance of the patient and their cancers to determine on-going cancer management, recurrence, treatment and survival status.

Reporting: The process of reporting to the central cancer registry (monthly), or national cancer databases (annually).

Uses of Cancer Registries

Registries can serve many purposes and provide value for a variety of healthcare stakeholders. It is an invaluable tool for evaluating cancer control programs and policies for a reduced cancer burden in a community.

Physicians and other healthcare professionals use cancer registries to evaluate available treatments, procedures, and therapies, and to understand how patients with different characteristics respond to various treatment.[8] Pharmaceutical companies and developers including medical device manufacturers use cancer registries to track and understand the effectiveness, safety, and value of medical devices or therapies and drugs entering or in the market. Researchers and developers use registry data as the foundation for registry-enhanced or registry-based research, clinical trials, or post market surveillance studies. Cancer patients share timely and personal data about their conditions and outcomes, and gain greater understanding of their care that leads to informed shared decision-making. Registries aid guideline development and help improve cancer prevention, research, and care; improves quality of life of patients with cancers and aid the implementation of procedures for improvement. Cancer registries provide information for decision support and cancer prevention activities and informs allocation of resources at local, state, and national levels. It equally guides educational program development for healthcare providers, patients, and the general public as well as offers career opportunity for cancer registrars. Cancer registries are notably useful sources of information on the burden of disease in a given population by providing information on incidence, mortality, and survival and less commonly on prevalence and disability adjusted life years (DALYs). Other important uses of cancer registry data include descriptive studies and analytical research into the etiology and risk factors of specific cancers. Finally, cancer registries form part of the body of knowledge used by medical professionals, epidemiologists, policymakers, and public health officials and is a form of population surveillance.

Standard Setting Agencies Guiding Cancer Registry Functions

A. National Program of Cancer Registries (NPCR) established in 1992, provides national leadership to Cancer Registries. Today, NPCR and SEER registries work collaboratively to collect and report cancer statistics on the entire U.S population. NPCR offers multiple educational and networking opportunities: annual national conference to build knowledge and expertise, promotion of professional standards and ethics, management of the CTR process and NCRA's Council on Certification, publication of a peer-reviewed scientific journal and a quarterly newsletter, web site offering a wide range of publications and information about educational opportunities.

B. Centers for Disease Control and Prevention (CDC): CDC has established national standards to ensure the completeness, timeliness, and quality of Cancer Registry data.
C. The International Cancer Control Partnership (ICCP) is a group of international organizations engaged in cancer control planning efforts. The Partners are seeking to create synergies to maximize collective resources and efforts to support the development, implementation and evaluation of national cancer control plans.
D. World Health Organization
E. Global Initiative for Cancer Registry Development (GICR)
F. African Cancer Registry Network
G. CanReg5 Webinar Series (IARC)

History of Cancer Registration in the World and Africa

The registration of cancer cases began with several unsuccessful attempts at cancer surveys in the United Kingdom in 1728, Germany in 1900, and the Netherlands and Spain in 1902 and 1908, respectively.[16] After several sporadic attempts at population-based cancer registration in Germany in 1926, USA, Denmark, England, and Canada in 1940s,[17] the need for the establishment of cancer registries throughout the world was recommended to the World Health Organization (WHO) by leading experts in the field of cancer control.[17] A few years later, the WHO established a subcommittee mandated to proffer recommendations for the establishment of cancer registries. The specialized arm of the WHO that deals with cancer, the International Agency for Research on Cancer (IARC) was formed in 1965 and the following year, the International Association of Cancer Registries (IACR) was founded.[16, 18] The IACR and IARC through their activities have promoted the development of cancer registration in many developing regions including SSA.

Cancer registration in Africa began in 1950s with registries in South Africa, Uganda, Nigeria, and Zimbabwe. These African registries contributed cancer incidence data to the WHO/IARC Cancer in five Continents (CIV) publications; Mozambique: Lorenco Marques, Nigeria: Ibadan, South Africa: Johannesburg, Bantu and Uganda: Kyadondu (Volume 1); South Africa: Cape Province, South Africa: Johannesburg, Nigeria: Ibadan, Zimbabwe: Bulawayo (Volume 2); Nigeria: Ibadan, and Zimbabwe: Bulawayo (Volume 3), until the late 1970s and 1980s when an economic recession and accompanying "brain drain" spread throughout Africa. Since then other registries that have contributed to subsequent CIV volumes include registries Dakar Senegal, Mali, The Gambia, and Harare Zimbabwe. Although, many African registries submit data for the CIV publication, data quality issues usually result in a good number of submissions being screened out. However, over the last decade, there has been a gradual reawakening of the need for cancer registries that can generate high-quality data with a resultant increase in the number of IARC acknowledged PBCRs (member registries of the African Cancer Registry Network) in Africa (ACRN). Countries like Nigeria, Kenya, Tanzania, Uganda, and Zimbabwe, have increasing cancer registries that are indispensable. These registries submit their cancer reports regularly and some registry members even sit on the NCCP board for making policies for their countries.

Cancer Registration in Nigeria

Nigeria, the most populous country in Africa with a population of approximately 168 million people represents over 50% of the population of the West African sub-region and slightly < 20% of the population of Africa.[19] In Nigeria, cancer registration began in 1960 with the first cancer registry located within the Pathology Department of the University College Hospital, Ibadan, in South Western Nigeria. Cancer incidence data from this registry were included in the first three volumes of Cancer Incidence in five continents (CIV) for the time periods 1960–1962, 1960–1965, and 1960–1969.[20]

Although, cancer registration began decades ago in Nigeria, progress over the past 50 years has been slow, patchy, and halting. Previous efforts at achieving quality population-based cancer registries have not been sustained. With the advent of democratic rule in Nigeria and improvements in public health financing and management, there has been a renewal of interest in cancer registration. In 2009, the Nigerian FMOH, Society of Oncology and Cancer Research of Nigeria and the Institute of Human Virology Nigeria (IHVN) conceptualized the Nigerian National System of Cancer Registries (NSCR) as a method for generating cancer incidence data that covers different sections of the country. The main objective of the NSCR is to provide training, capacity development, mentoring, technical, and scientific support to cancer registries in Nigeria to enable them attain population-based cancer registration status and generate high-quality cancer incidence, treatment, and survival data for the country.

There are 20 Hospital-based cancer registries (HBCR) in Nigeria: Ahmadu Bello University Teaching Hospital, Zaria (ABUTH) Cancer Registry, Aminu Kano Teaching Hospital, Kano (AKTH) Cancer Registry, Federal Medical Centre, Abeokuta Cancer Registry, Federal Medical Centre, Keffi Cancer Registry, Federal Medical Centre, Gombe Cancer Registry, Federal Medical Centre, Lokoja Cancer Registry, Federal Medical Centre, Owo Cancer Registry, Federal Medical Centre, Yenagoa Cancer Registry, Imo State University Teaching Hospital, Orlu (IMSUTH) Cancer Registry, Jos University Teaching Hospital, Jos (JUTH) Cancer Registry, Lagos State University Teaching Hospital, Ikeja (LASUTH) Cancer Registry, Lagos University Teaching Hospital, Surulere (LUTH) Cancer Registry, Nnamdi Azikiwe University Teaching Hospital, Nnewi (NAUTH) Cancer Registry, Obafemi Awolowo University Teaching Hospital, Ile-Ife, (OAUTH) Cancer Registry, Rivers State University Teaching Hospital, Orogbum, Port Harcourt Cancer Registry (formerly Braithwaite Memorial Specialist Hospital Cancer Registry), University of Benin Teaching Hospital, Benin (UBTH) Cancer Registry, University of Ilorin Teaching Hospital, Ilorin (UITH) Cancer Registry, University of Port Harcourt Teaching Hospital, Port Harcourt (UPTH) Cancer Registry, University of Maiduguri Teaching Hospital, Maiduguri (UMTH) Cancer Registry, and University of Uyo Teaching Hospital, Uyo (UUTH) Cancer Registry.[19]

The NSCR coordinates the activities of the cancer registries and generates aggregate national cancer incidence, treatment, and survival data; disseminate the data to relevant government agencies for use in policy formulation and resource allocation; to scientists conducting cancer research; and to the public for education, awareness, and advocacy purposes. The NSCR also advocates for cancer registration in the country, increase awareness of cancer, advocate, and publish locally relevant cancer data. In order to achieve these objectives, NSCR works to strengthen existing cancer registries, establish new registries through the provision of training, mentoring, computer hardware and software, and provide support for data management.

Population Based Cancer Registries (PBCR) in Nigeria

There are thirteen population-based cancer registries (PBCR) in Nigeria.[19]

Ibadan Cancer Registry (IBCR)*:* The first Cancer Registry in Nigeria established in 1962, located within the Department of Pathology at the University

College Hospital, Ibadan. Cancer incidence data from this registry were published for the time periods 1960 - 1962, 1960 - 1965, and 1960 - 1969 in the first three volumes of Cancer Incidence in 5 Continents (CIV). IBCR became defunct in 2002, but was revived in 2009. Data from this registry has been presented in the first 3 volumes of the Cancer in 5 continents publication by IARC (CIV), the IARC scientific publication No. 153, Cancer in Africa and also in GLOBOCAN 2012 where data from this registry along with the Abuja and Calabar PBCRs were used to derive national estimates for Nigeria.

***Abuja Cancer Registry (ABCR)**:* The Abuja Cancer Registry started operation as a hospital-based registry in 2006. It is situated in the National Hospital Abuja in Nigeria's Federal Capital Territory (FCT). With the collaboration of Federal Ministry of Health and the Nigeria National System of Cancer Registries, it graduated to become a population-based cancer registry in January 2009. The registry falls under the Oncology Department and the Medical Records Department. Both departments are important stakeholders (AFCRN CIA III, 2019). The Registry is population-based for Abuja City and Abuja FCT. The registry utilizes the sources of information available at the hospital including, pathology laboratory, medical records department, oncology department and in-patient wards, and out-patient clinics and employs both active and passive methods of case-finding. Data are also collected from 9 hospitals (both public and private) in the FCT. Four pathology laboratories also supply pathology reports to the registry. Registry staff visit departments and units in the nine hospitals to register cases from the Oncology departments, in-patient wards and out-patient clinics. All cancer cases that are identified at the various sources of information are registered, including those in non-residents. Non-resident cases are however excluded from the analysis. Death certificates are accessed and abstracted. Data are recorded on the cancer registry abstract form. The CanReg 4 system is used for data processing and management.[11]

Other population-based registries in Nigeria include: Enugu Cancer Registry (ECR), established in 1988 as a hospital-based cancer registry, Sokoto Cancer Registry (SCR), established in 2013, Ekiti Cancer Registry, Kebbi Cancer Registry, Calabar Cancer Registry, Asaba Cancer Registry, Ijebu Cancer Registry. Presently, a total of 30 cancer registries in Nigeria are members of NSCR. These include: 10 population-based cancer registries (PBCR) and 20 hospital-based cancer registries (HBCR).[19] Data from Cancer Registries across the country, as reported by the Nigerian National System of Cancer Registries (NSCR), has been very useful in the formulation of evidence-based cancer control policies and programs. The activities of NSCR have improved cancer research in Nigeria and have been a reliable source of epidemiological data from Nigeria to GLOBOCAN, the global Cancer research agency.[19]

Recommendation

Successful implementation of cancer registration is essential and improving both the quality as well as quantity of population-based registries in Africa is critical in ensuring that cancer prevention and control interventions are on course. This requires cooperation of many stakeholders in the health and non-healthcare sectors, including private and public oncology care and pathology services providers, medical records, vital statistics, community leaders, patients, and government officials. To obtain effective coordination of cancer registration, all stakeholders involved must work together. The primary healthcare system needs to be fully functional for successful establishment and sustenance of population-based cancer registries which are the best option at measuring and understanding cancer burden in a country by providing national estimates.[30] Advocacy at the level of the hospital is particularly instrumental in ensuring sustainability of the program. Engaging heads of institutions, heads of medical records, and cancer registry directors is crucial to generating much needed local support for the cancer registries. Hospitals need be mandated to set up Cancer Registry Management Committees that can oversee the function and administration of cancer registries. These committees can advocate to hospital management, government, and society on behalf of cancer registries. Often identified as integral to the success of any cancer registry is the leadership of the registry. The director of a cancer registry is expected to play a supervisory role, be involved in monitoring the activities of the cancer registrars particularly as regards data abstraction and recording as well as possess the ability to engage all stakeholders with skill, diplomacy, and tact. Registries in institutions where the leadership is interested in cancer registration have often fared better than those where this is lacking. In most institutions where the cancer registry staff is deployed from the medical records department and may be rotated out of the registry after they have undergone several cancer registry trainings with new persons brought in with no knowledge of cancer registration principles or use of the relevant software, this scenario can be prevented by securing the support of the head of the medical records department.

Conclusion

Cancer registries are at the core of the global monitoring framework of non-communicable diseases-cancer. It plays a vital role in the collection of important data about each new patient diagnosed with cancer and is treated. Many healthcare givers and researchers utilize the high-quality data that can be found in Cancer registry in order to conduct research and for the analysis of patients and their disease. It is cost-effective and assists countries of the world in setting priorities by identifying cancers with the highest burden, planning for emerging trends, focusing research where it is needed, and allocating resources. It is an invaluable tool for the evaluation of cancer control program. It is hoped that GICR and AFCRN can help to measurably improve the availability and quality of cancer registry data in sub-Saharan Africa in the coming years, so that the surveillance map of a decade from now will be a clear advance on what we observe today.

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