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The Role of Hospital-Based Cancer Registries in Low and Middle Income Countries – The Nigerian Case Study

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Abstract

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Conflict of Interest Statement

The authors declare no conflict of interests.

Contributors

EJA and MPC analyzed and interpreted the data and wrote the first draft and subsequent revisions. CAA contributed to the methodological approach, revised several versions of the draft, obtained funding and guided all aspects of this report. All other authors contributed equally to this study by providing feedback and contributing to the final draft.

Background—The incidence of cancer continues to rise all over the world and current projections show that there will be 1.27 million new cases and almost 1 million deaths by 2030. In view of the rising incidence of cancer in sub-Saharan Africa, urgent steps are needed to guide appropriate policy, health sector investment and resource allocation. We posit that hospital based cancer registries (HBCR) are fundamental sources of information on the frequent cancer sites in limited resource regions where population level data is often unavailable. In regions where population based cancer registries are not in existence, HBCR are beneficial for policy and planning.

Materials and Methods—Nineteen of twenty-one cancer registries in Nigeria met the definition of HBCR, and from these registries, we requested data on cancer cases recorded from January 2009 to December 2010. 16 of the 19 registries (84%) responded. Data on year hospital was established; year cancer registry was established, no of pathologists and types of oncology services available in each tertiary health facility were shown. Analysis of relative frequency of cancers in each HBCR, the basis of diagnosis recorded in the HBCR and the total number of cases recorded by gender was carried out.

Results—The total number of cancers registered in these 11 hospital based cancer registries in 2009 and 2010 was 6484. The number of new cancer cases recorded annually in these hospital based cancer registries on average were 117 cases in males and 177 cases in females. Breast and cervical cancer were the most common cancers seen in women while prostate cancer was the commonest among men seen in these tertiary hospitals.

Conclusion—Information provided by HBCR is beneficial and can be utilized for the improvement of cancer care delivery systems in low and middle income countries where there are no population based cancer registries.

Keywords

Hospital based cancer registries (HBCR); population based cancer registries (PBCR); low and middle income countries (LMIC)

Background

Cancer has become a major global public health problem. In 2008, there were 12.7 million new cases of cancer and 7.6 million cancer related deaths worldwide.(1) Africa, with a population of approximately 1 billion people (15% of the world's population) contributed 681,000 new cancer cases (5% of all cases worldwide) and 512,000 deaths (7% of all cancer deaths) to the worldwide estimates in 2008.(2)The incidence of cancer continues to rise all over the world and current projections show that there will be 1.27 million new cases and almost 1 million deaths by 2030.(2) Low and middle income countries (LMIC) will contribute more than 80% of the new cases worldwide.(2)

Africa continues to face challenges arising from sustained epidemics of infectious diseases such as malaria, HIV/AIDS and Tuberculosis.(3)In the past decades, as life expectancy on the continent improved and the risk of death from infectious diseases declined, the incidence of non-communicable diseases including cancer has been rising significantly.(4)Most of the increase in cancer incidence in Africa is attributable to this increase in life expectancy but changing dietary and physical activity patterns, tobacco use, and the advent of the HIV-AIDS epidemic are major contributors.(2, 5, 6)

In view of the rising incidence of cancer in sub-Saharan Africa, urgent steps are needed to guide appropriate policy, health sector investment and resource allocation. To be effective, these interventions need to be guided by data on the incident and prevalent cancers so that limited resources can be used effectively and efficiently. Monitoring cancer incidence is an

important part of this requirement and the classic approach has been through implementation of cancer registration.

Cancer registration can either be population or hospital based. Population based cancer registries (PBCR) are the gold standard for obtaining accurate cancer incidence in any given population but they are more resource intensive compared to hospital based registries. There are 62 PBCRs in Africa but only 5 produced data of sufficient quality to be included in the IARC publication of worldwide cancer incidence – Cancer in Five Continents (CIV) in 2007.(7) As of 2006, almost 80% of the world's populations were not covered by PBCR and most of these live in low and middle income countries (LMIC).(8)

Efforts at sustainable PBCR in developing countries are stymied by inadequate funding, lack of personnel and a general lack of understanding of the need of PBCR. In contrast there is a large number of Hospital Based Cancer Registries (HBCR) in LMIC but literature describing their role and how best data obtained from them can be used is sparse. We posit that HBCR are fundamental sources of information in limited resource regions where population based cancer registries are lacking. Although HBCR are not useful to monitor the effects of cancer screening, they give an indication of the demand for cancer care services and other information that is useful for policy and planning. They are recognized in the literature as an integral part of hospital cancer control programs and have an indispensable role in a country's health care delivery system.(9)

This paper provides information on HBCR in Nigeria, Africa's most populous and diverse country. We analyze data from 11 HBCR that are part of the National Cancer Registry Program in Nigeria from 2009 to 2010 and describe the role of hospital cancer registries and how their data can be beneficial to improve health care systems in low and middle income countries in general.

Materials and Methods

Over the past 3 years, the Institute of Human Virology, Nigeria and the Nigerian Federal Ministry of Health have collaborated on training and streamlining the activities of cancer registries in Nigeria. During this period, 21 institutions have been trained and provided support for cancer registration. Of these 19 met the definition of HBCR (2 met the criteria for Population Based Cancer Registries) and we requested data on cancer cases recorded by these registries from January 2009 to December 2010. Most, 16 of the 19 registries (84%) responded.

No data was received from 3 cancer registries - University of Uyo Teaching Hospital, Uyo (UUTH), Federal Medical Centre, Lokoja and Federal Medical Centre, Keffi. No data on hospital facilities could be obtained from one hospital – Lagos State University Teaching Hospital, Ikeja (LASUTH). We excluded data from 5 institutions namely Lagos University Teaching Hospital, Suru-Lere (LUTH), Jos University Teaching Hospital, Jos (JUTH), Aminu Kano Teaching Hospital, Kano (AKTH), Federal Medical Centre, Gombe and University of Benin Teaching Hospital, Benin (UBTH) because of incomplete data (>50% missing entries for incidence date and age).

We analyzed data from 11 HBCR namely; University of Nigeria Teaching Hospital, Enugu (UNTH), University of Ilorin Teaching Hospital, Ilorin (UITH), University of Port Harcourt Teaching Hospital, Port Harcourt (UPTH), Federal Medical Centre, Ekiti (FMC IdoEkiti), University of Calabar Teaching Hospital, Calabar (UCTH), Obafemi Awolowo University Teaching Hospital, Ile-Ife, (OAUTH) Nnamdi Azikiwe University Teaching Hospital, Nnewi (NAUTH), Lagos State University Teaching Hospital, Ikeja (LASUTH), University

of Abuja Teaching Hospital Gwagwalada(UATH), and the Ahmadu Bello University Teaching Hospital, Zaria (ABUTH).

All these registries used Canreg4 software for data entry and management and ICD-O 3 for classification and coding. CANREG4 software prevents the use of non-existent codes and performs checks for internal consistency between variables. Data abstracted by the hospital cancer registries included information on name, age, morphology and topography of tumor, tribe, address, treatment, education level, marital status, religion and cause of death. We supplemented these data with information from unpublished work (reports and direct correspondence with the Federal Ministry of Health).

Analysis

We analyzed data on year hospital was established; year cancer registry was established, no of beds, no of pathologists and types of oncology services available in each tertiary health facility. We also analyzed relative frequency of cancers in each HBCR. We describe the basis of diagnosis recorded in the HBCR, the total number of cases recorded by gender and relative frequencies of the most common cancers seen. We attempted to estimate incidence rates using the population of the region covered by the HBCR and then using residential addresses to exclude cases referred from other regions. We also excluded cases with incomplete or inaccurate address entries, but after the exclusions the cases left were too few for any meaningful analysis.

Results

Most HBCR in Nigeria started functioning about 10 years with 6 of the 11 HBCR described in this study established in 2009, when the Nigerian National Cancer Registry program began. The average bed capacity of the hospitals where these HBCR are located is 469 beds per hospital. There were an average of 5 pathologists and 24 surgeons per hospital, excluding surgeons in training. The term, 'surgeon' as used in this communication is inclusive of all surgical subspecialties. All these hospitals offer chemotherapy services (Table 1).

The total number of cancers registered in these 11 hospital based cancer registries in 2009 and 2010 was 6 484 (Table 2 and Figure 1). Overall, more cases were recorded in women (3 903 – 60.2%) than in men (2 581 – 39.8%). Two hospitals, UNTH Enugu and ABUTH Zaria recorded the highest number of cases (Table 2). These were also the only hospitals out of the 11 that offer radiotherapy services. However, the radiotherapy service at UNTH was not functional at the time of writing this report. The number of new cancer cases recorded annually in these hospital based cancer registries on average were 106 cases in males and 164 cases in females (Table 2). The commonest basis for cancer diagnosis was histology of the primary tumor accounting for 70% while cytology accounted for 16.6% and clinical diagnosis was the basis in 9.5% of all cases (Table 3).

We identified the 5 most common cancers registered by gender in the 2 year period under review. In males, cancer of the prostate (29.2%) was the most common cancer reported followed by colorectal cancer (7.0%), lymphomas (6.8%), liver cancer (4.0%) and skin cancer (3.8%) (Table 4). In women, breast cancer was by far the most common cancer constituting 40.3% of all cancers followed by cervical cancer (17.3%), cancer of the ovary (3.7%), lymphomas (3.1%) and skin cancer (2.1%) (Table 4). Overall, all other anatomical cancer sites excluding the 5 commonest cancers, accounted for 50% of all cancers in males and 33% in females.

Discussion

Our study showed that cancer registration is growing in Nigeria with many of the HBCR reported in this paper starting in the last few years. Over the 2 years covered by this report, about 6000 new cancer cases were reported by 11 hospital based cancer registries in Nigeria. The commonest cancer in women was breast cancer while prostate cancer was the commonest cancer in men. The hospitals commonly used histology of the primary tumor as basis of diagnosis but cytology and clinical diagnosis were also reported by some hospitals while registration by death certificate only, is negligible.(10) While HBCR data are prone to referral bias and cannot give a reliable measure of cancer incidence or provide information on cancer trends in a given population, they can provide data on the most frequent cancers managed in the hospitals that provide cancer care services.

Our finding of high prevalence of prostate cancer is consistent with studies from other parts of the world (11, 12) and with data from our population based cancer registry (manuscript in press). Colorectal cancer is the 2nd commonest cancer in males but the proportion is substantially less common compared to prostate cancer. The 3rd and 4th commonest cancers in men (lymphomas and liver cancer) were those associated with oncogenic virus infections. (13)

Breast cancer was the commonest female cancer recorded by these HBCR. This cancer is also the commonest incident cancer in Nigerian women as reported by population based cancer registries in Nigeria. (data not shown) Incidence of breast cancer in LMIC is expected to continue to rise with increasing life expectancy, changing obstetrics and gynecology practices, diet and physical activity.(14–16) It was responsible for almost half of all cancers reported in women and is the most common cancer reported in both sexes combined. The biggest challenge of breast cancer management in LMIC is low awareness and limited access to diagnosis and treatment(17). Given the high prevalence and high case fatality rates of breast cancer in LMIC, increased awareness, early detection and prevention should be priority control strategies for LMIC.(17)

Cancer of the cervix is the 2nd most common female cancer (18%) reported by these hospital based cancer registries. This is consistent with the GLOBOCAN 2008 data and data from our population based cancer registries (data not shown). [1] Cervical cancer prevention has been effective in developed countries (18, 19) but has been a challenge in LMIC. [16] [17] Recent efforts using “screen and treat”, leveraging resources for HIV/AIDS prevention and HPV diagnosis based screening methods may prove more successful.(20–24)

Skin cancer was the fifth most common cancer treated at these hospitals and it was more common in males (3.8%) than in females (2.1%). This was surprising since black populations have a low incidence of skin cancer. All cases recorded by the HBCR were basal cell and squamous cell carcinoma. This suggests that non-melanoma skin cancer (NMSC) may not be as rare as claimed in black populations. Similar findings were described in the early nineties in Uganda. [18] Albinism, a risk factor for NMSC in Africa may be a major contributing factor.(25, 26)

The 11 hospitals based cancer registries discussed in this paper are located in major tertiary health institutions that serve large populations and are referral sites for cancer management in Nigeria. Many of these hospitals lack radiotherapy services similar to the situation in many other LMIC.(27–29) Of the 54 Federal Health Institutions in Nigeria, only 3 (UCH Ibadan, National Hospital Abuja and ABUTH Zaria provide radiotherapy services and even in these hospitals, services are frequently episodic. All the hospitals reported availability of chemotherapy but none reported having medical oncology services or specialized chemotherapy units.

Taken together, cancers of the breast and cervix constitute about 60 % of all cancers presenting among Nigerian women treated in major tertiary health centers. Our population based cancer registry data also show that these 2 cancers were the commonest cancers affecting Nigerian women. (data not shown) Health care delivery models that incorporate prevention and care of these 2 cancers into women's health care services are likely to contribute to significant reductions in cancer morbidity in Nigeria.

Apart from lymphomas in men, there was no evidence of the expected marked increase in AIDS associated cancers in this data.(30, 31) The prevalence of HIV/AIDS in Nigeria is 3.6% with an estimated 2 900 000 [95% CI 2 600 000– 3 200 000] persons living with HIV/AIDS.(32, 33) Of these, about 50% are receiving care and treatment.(33) It is therefore expected that a significant number of AIDS Associated cancers will be found in this population, although there is insufficient data on the actual incidence and prevalence.(6) This may be due to poor linkage of data and records between cancer and HIV programs, non-diagnosis of cancers in HIV patients and high fatality rate among the HIV+ populations with poorly controlled HIV infection.(6, 14) As health care services for this population improves, it becomes important to promote awareness of cancer and early diagnosis while strengthening the referral systems at the primary and secondary levels (34, 35).

While HBCR data are limited by inability to provide incidence data, they provide useful information that can guide resource allocation, cancer care policies and priorities, and investment in cancer prevention services. HBCR can be useful in describing patterns of referral and thus can define the catchment area of a given hospital. These data can be used to calculate the success of follow-up of cancer patients in a given hospital. In addition, HBCR data may be reflective of the nature and sophistication of services available within the health care system. Easily biopsied cancers like breast and skin maybe over-represented in HBCR data particularly where pathology is the commonest diagnostic tool used.

Despite these limitations, the findings of the most frequent cancers reported by HBCR in this study is similar to the findings from Nigerian population-based cancer registries and the most common cancers in Nigeria reported in GLOBOCAN 2008. [1]

Conclusion

Cancers are a new threat to the already overburdened health care system in many low and middle income countries.(28) Most LMIC have poor cancer surveillance systems and lack financial, human and infrastructural resources for effective cancer prevention, management and control.(36) Our study has important implications for cancer management in these settings. We propose the use of HBCR as sources of actionable cancer information and highlight their activities in a typical LMIC. Establishing and sustaining HBCR or PBCR in developing countries is difficult but need not be an either or proposition since both types of registries can provide useful information for cancer prevention and control. Nevertheless, upgrading hospital based cancer registries to population based registries in these regions should be paramount, despite the challenges.

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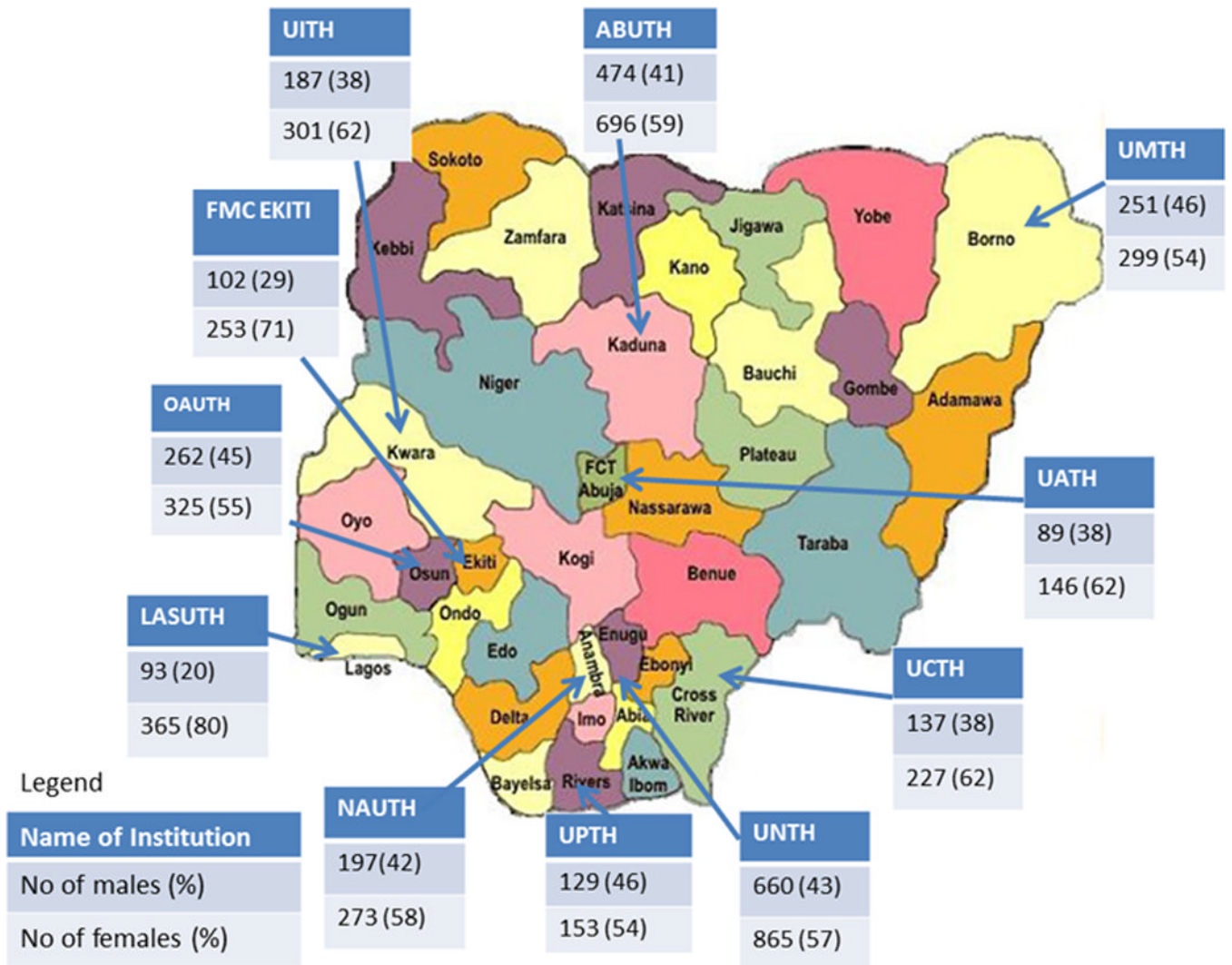


Figure 1. Map of Nigeria showing HBCR and total number of cases recorded by gender in each registry

Table 1

Description of facilities at 11 hospitals with HBCR in Nigeria, 2011

Hospital Cancer Registry	Year Hospital was founded	Year cancer registry began	Hospital Capacity (No of Beds)	No of Pathologists	No of Surgeons	Radiotherapy/unit	Chemotherapy /Surgery Services
NAUTH	1990	2009	350	5	29	No	Yes
UMTH	1983	2003	400	4	20	No	Yes
UCTH	1979	1983	451	5	29	No	Yes
FMC Ido-EKITI	1998	2009	276	5	10	No	Yes
UNTH	1966	1988	500	5	29	Yes (Not Functional)	Yes
UATH	1993	2009	350	2	18	No	Yes
ABUTH	1967	1970	593	6	18	Yes	Yes
UITH	1980	1990	445	6	17	No	Yes
LASUTH	-	2009	-	-	-	No	Yes
OAUTH	1975	1989	617	6	25	No	Yes
UPTH	1980	2009	700	7	40	No	Yes

Table 2

Number and proportion of cancer cases reported by 11 Nigerian hospital based cancer registries, 2009–2010

Hospital Registry	Male	Female	Total
NAUTH	197 (41.9%)	273 (58.1%)	470
UMTH	251 (45.6%)	299 (54.4)	550
UCTH	137 (37.6%)	227 (62.4%)	364
FMC EKITI	102 (28.7%)	253 (71.3%)	355
UNTH	660 (43.3%)	865 (56.7%)	1525
UATH	89 (37.8%)	146 (62.2%)	235
ABUTH	474 (40.5%)	696 (59.5%)	1170
UITH	187 (38.3%)	301 (61.7%)	488
LASUTH	93 (20.3%)	365 (79.7%)	458
OAUTH	262 (44.7%)	325 (55.3%)	587
UPTH	129 (45.7%)	153 (54.3%)	282
Total	2 581 (39.8%)	3 903 (60.2%)	6 484

Table 3

The basis of diagnosis reported by 11 HBCR in Nigeria, 2009–2010

Basis of diagnosis	Clinical	Death Certificate	Cytology	Histology of Metastases	Histology of Primary	Unknown	Total
HBCR							
NAUTH	296	-	1	1	172	-	470
UMTH	-	13	-	-	537	-	550
UCTH	12	8	55	10	279	-	364
FMC EKITI	-	-	107	3	244	1	355
UNTH	206	0	321	1	997	-	1525
UATH	4	1	104	26	100	-	235
ABUTH	2	-	164	25	979	-	1170
UITH	11	-	126	37	314	-	488
LASUTH	3	1	47	10	332	65	458
OAUTH	-	-	-	-	587	-	587
UPTH	-	6	39	-	237	-	282
TOTAL	534 (8.3%)	29 (0.4%)	964 (14.9%)	113 (1.7%)	4778 (73.7%)	66 (1.0%)	6484 (100%)

Table 4

The commonest five cancers in males and females reported by 11 HBCR in Nigeria, 2009–2010

Males	Males		Females		Number	%
	Number	%	Number	%		
Prostate	754	29.2	Breast		1446	40.0
Colorectal	181	7.0	Cervix		645	17.9
Lymphomas	177	6.8	Ovary		134	3.7
Liver	104	4.0	Lymphomas		110	3.1
Skin Cancer* (Excluding Melanoma of the skin)	98	3.8	Skin Cancer* (Excluding Melanoma of the skin)		83	2.1