

HISTORY OF CANCER REGISTRATION IN THE WORLD AND IN NIGERIA

BY

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INTRODUCTION

Cancer Registration:

- continuing systematic collection of data on the occurrence and characteristics of reportable neoplasms
- Population-based cancer registry records information on all new cases occurring in a defined population
- Hospital-based cancer registry concerned with improving cancer patient care and evaluation of treatment
- Surveillance of cancer crucial in formulating a cancer control programme and monitoring its success

GLOBAL CANCER BURDEN

- Approximately 20 million people are living with cancer worldwide
- By 2020, number expected to exceed 30m
- Of 10 million new cancer cases seen globally yearly,
- 5.5m are in less-developed and 4.7m in more developed countries
- Cancer currently causes 12% of all deaths worldwide
- In about 20 years time, no. of annual cancer deaths will increase from 6m to 10m
- At least a third of the new cases of cancer seen each year are preventable through control of tobacco and alcohol use, moderate diet and immunizing against viral hepatitis B. (WHO, 2002)

EARLY YEARS OF CANCER REGISTRATION

- Cancer registration began as a slow process
- 1728, in London first unsuccessful attempt
- 1900, in England and Germany demands were made for improved statistical investigations on spread of cancer in the population
- 15th Oct. 1900 in Germany questionnaire registration of cancer patients under treatment
- 1902 similar approach used in the Netherlands, Spain, Portugal, Hungary, Sweden, Denmark, and Iceland
- Failure reported in Germany as <50% of Physicians returned the questionnaire
- 1904 in Heidelberg and 1906 in Baden attempts at countrywide cancer morbidity survey failed
- 1905, Bushford and Murray report of the Imperial Cancer Research Fund advised against a cancer census based on failed efforts in Germany

FURTHER ATTEMPTS AT CANCER REGISTRATION

- 1930, in USA, Wood suggested cancer be made a notifiable disease with compulsory registration of all cancer cases
- 1927 in Massachusetts a pilot cancer registration exercise considered a failure as only 1/3 of cancer cases were reported (Hoffman, 1930)
- 1937, continuous recording of individuals with cancer began in Mecklenburg
- Aimed at producing cancer morbidity statistics (Lash, 1940)
- Registration forms or cards were used and reports checked and entered into a card index
- Registration rated as fairly well with a coverage of 200 new cancer patients/100,000 inhabitants in 1937-38
- 1939 similar investigations held in Saxony-Anhalt in Saarland and in Vienna, Austria
- Efforts were discontinued in both places due to political developments

MODERN DEVELOPMENTS

- 1929, Hamburg Cancer Registry the oldest example of modern cancer registry was established
- Based on the idea that cancer control involves not only medical and scientific but also public health and economic aspects
- Started in 1926 when a private after-care organization of cancer patients was founded
- In 1929, official status obtained as the follow-up patient care service of the Hamburg Public Health Department
- 3 nurses visited hospitals and medical practitioners in Hamburg at regular intervals
- Names of cancer patients records were transferred to a central index at the Health Department
- Card index compared weekly with official death certificates and formed the basis of the Hamburg Cancer Registry(Keding,1973)

Population –based cancer Registration in USA

- 1935 in USA, a population-based cancer registration began in Connecticut
- Had epidemiological and ecological objectives
- Connecticut State Department of Health formed a division of cancer research
- Aims: “To investigate concerning cancer, the prevention, treatment thereof, mortality therefrom, and to take appropriate actions to reduce mortality due thereto”.
- 1941, the Connecticut Tumour Registry began statewide operation

FURTHER CANCER REGISTRIES

- Early in 1940's more cancer registries established in USA and Canada (Stocks, 1959, Barclay, 1976)
- Danish Cancer Registry founded in 1942 under auspices of the Danish Cancer Society
- Oldest functioning Cancer Registry covering a national population
- Voluntary cancer reporting by Physicians assisted by the Danish Medical Association
- National Board of Health gave full access to death certificates and all mortality data

Task of the Danish Cancer Registry

Collection of data serving as a basis :

- For individual follow-up of patients
- For reliable morbidity statistics with a view to an accurate estimate of therapeutic results
- For an accurate evaluation of variations in incidence of malignant neoplasms, secular as well as geographical occupational etc(Clemmesen,1965)

Table 1.0 :Population-based cancer registries established before 1955

Country (region)	Year of establishment	Notification
• FR Germany (Hamburg)	1929	Voluntary
• USA (New York State)	1940	Compulsory
• USA (Connecticut)	1941	Compulsory (since 1971)
• Denmark	1942	Compulsory (since 1987)
• Canada (Saskatchewan)	1944	Compulsory
• England and Wales (S.W. Region)	1945	Voluntary
• England and Wales (Liverpool)	1948	Voluntary
• New Zealand	1948	Compulsory
• Canada (Manitoba)	1950	Voluntary
• Yugoslavia (Slovenia)	1950	Compulsory
• Canada (Alberta)	1951	Compulsory
• USA (El Paso)	1951	Voluntary
• Uganda (Kampala)	1951	Voluntary
• Hungary (Szabolcs, Miskolc, Vas)	1952	Compulsory
• Norway	1952	Compulsory
• USSR	1953	Compulsory
• German Democratic Republic	1953	Compulsory
• Finland	1953	Compulsory (since 1961)
• Iceland	1954	Voluntary

Source: IARC/WHO(1991)

Cancer Registration in Africa

- Sparse information on Cancer registration as cancer was thought to be rare
- Early registries set up in 1950's
- Knowledge of cancer patterns based primarily on work by pioneer clinicians and Pathologists
- Description of cancer case series by age, sex site and morphology
- Reviews of cancer types reported as relative frequencies
- Pathology series often biased with over representation of easily biopsied cancers and paucity of some e.g.liver, brain or pancreas
- **1951, Kampala** first population-based cancer registry in tropical Africa established in Uganda, voluntary case notification
- Located in Makerere Medical school under Prof. J.N.P.Davies
- **1960, Ibadan** Cancer registry, first population-based registry in Nigeria
- Established in Department of Pathology, UCH by late Professor G.M.Edington
- Case notification by regular visits of Registry staff to clinics and hospitals
- Also recorded all malignancies diagnosed in the Department of Pathology
- Stopped in 1994 due to lack of funds but resumed 3 years later
- **1985, Zimbabwe National** Cancer Registry, established in Harare, Zimbabwe
- **1986, The Gambia National Cancer Registry**, established as part of the Gambia Hepatitis intervention study project
- Located in the Medical Research Council, Banjul and covers the whole country
- Decentralised in 1997 to cover all major hospitals
- **1986, Mali** Cancer Registry covers the population of Bamako
- Located in the Department of Pathology of the National Institute of Public Health Research
- **1988 France La Reunion** Cancer Registry became population –based, started 1983
- **1990's Algiers** Cancer Registry covers the Walaya of Alger a costal area in the North of Algeria
- **ALL AFRICAN CANCER REGISTRIES HAVE VOLUNTARY CASE NOTIFICATION**

Table 2.0: African Cancer Registries in CI5 1950 -1997

Vol.	Period	Registries	Population
1	1950's	4	4
11	1956-67	4*	7
111	1968-72	2*	2
1V	1973-1977	1	1
V	1978-1982	0	0
V1	1983-87	3	3
V11	1988-92	5	6
V111	1993-1997	6	6

Note: No contributions from Africa in CI5 Vol. V (1978 -82)

WORLDWIDE CANCER REGISTRATION

- 1946, conference held in Copenhagen under the initiative of Dr Clemmesen Director of Danish Cancer Registry
- Served as impetus for establishment of cancer registries worldwide(Schinz,1946)
- 12 internationally leading experts in cancer control recommended the worldwide establishment of cancer registries to the interim commission for the WHO(Clemmesen,1974)

RECOMMENDATIONS TO WHO BY CANCER CONTROL EXPERTS

- Great benefit of collection of cancer patient data from as many countries as possible suggested
- Recording of such data on agreed plan so as to be comparable
- Each nation should have a central registry to arrange for the recording and collection of such data
- An international body to over see and correlate the data and statistics obtained in each country

International Cancer Registration Begins

- 1950, WHO established a subcommittee on cancer registration and their statistical presentation
- Recommendations for establishment cancer registries worked out (Stock, 1959)
- UICC arranged an international symposium on Geographical Pathology and Demography of Cancer emphasis on enumeration of new cases in a defined area made (Clemmesen, 1951)
- UICC established a committee on Geographical Pathology based on recommendations of the symposium

IARC AND IACR

- 1965, WHO established IARC, the International Agency for Research on Cancer, a specialised cancer research centre
- IARC based in Lyon, France
- 1966, in Tokyo, Japan, IACR, the International Association of Cancer Registries was formed
- IACR is a membership organization for Cancer Registries and collaborates with IARC
- **IARC** Collects and analyses data on Cancer incidence with the end results of cancer treatment in defined populations
- Publishes data in **Cancer incidence in 5 continents** regularly from several population-based cancer registries
- Published **Guidelines for standardized hospital-based cancer Registries and Cancer Registration and its techniques**
- 1991 Published **Cancer Registration: Principles and Methods**
- **GLOBOCAN 2002, Cancer incidence, mortality and prevalence worldwide** IARC Cancer Base no.5 version 2 publication
- Involved in training manpower in Cancer registration and Epidemiology and assists in establishment of new population-based cancer registries when funds are available
- No. of population-based Cancer Registries increased from 32 in 1966 to 186 in 2002

Cancer Registration in Nigeria

CHALLENGES:

- No National Cancer Registration till date in Nigeria
- Early attempt in 1990's-early 2000's unsuccessful
- Cancer not yet a priority of the Health Ministry as infectious diseases pose immediate and greater challenges
- Inadequate health budgetary allocation to Cancer control at all levels of Government
- Uncoordinated cancer registration in various centres
- Resource limitation restricts access of populace to health facilities
- Cases only found when they come in contact with health services
- Poor funding of existing population based cancer registries
- Lack of trained personnel e.g. epidemiologists, statisticians
- High rate of change in registry personnel especially trained ones
- Valid population census data often difficult to obtain and census infrequent
- Lack of vital statistics e.g. No compulsory death registration and death certification
- Lack of National identity no. for citizens

LOCATION OF CANCER REGISTRIES IN NIGERIA

➤ Population-based cancer registries:

SW: Ibadan

SS: Calabar

NE: Maiduguri

➤ Hospital-based ca registries:

SW: Lagos, Ife-Ijesha, Eruwa

SE: Enugu,

NC: Zaria, Kano

NW: Ilorin



Early years of Cancer Registration in Nigeria

- Ibadan Cancer Registry established in 1960
- Some hospital-based tumour registries established in 70's ,80's and 90's
- ABU, Zaria Cancer Registry, 1982 by Ed 'B Attah
- UCTH, Calabar Cancer Registry, 1983 by Ed 'B Attah and Ima-Obong Ekanem
- UNTH, Enugu Cancer Registry, 1988, by Nene Obianyo
- OAUTHC, Ife-Ijesha Cancer Registry, 1988 by W Odesanmi and Olusegun Ojo
- UMTH, Maiduguri Cancer Registry, 1995 by MIA Khalil and Ima-Obong Ekanem
- LUTH, Lagos Cancer Registry, 1998 by Debo Adeyemi
- UITH, Ilorin Cancer Registry, ?1990's by Afolayan

Recent years of Cancer Registration in Nigeria

- 1990 NHCRN established by Government, located in UCH Ibadan
- 2002 death of pioneer chairman NHCRN, late Prof. T.F. Solanke stalled effort to collate national cancer data
- 2004 April, Calabar Cancer Registry became population-based following visit by IARC official in 2003
- 2006 FMOH facilitated Fulbright Scholar's evaluation of status of cancer registration in Nigeria
- 2000's IARC sponsored training of Cancer registry staff in Cancer epidemiology and registration using CANREG
- Mid-2000, local training of cancer registry personnel in cancer registration methods in UCH, Ibadan
- Increased awareness for setting up a National Cancer Registration
- National population census conducted by National population commission, 2006
- 2007 June, Maiduguri Cancer Registry became population-based
- 2008 August, Nigeria Cancer Registry Training Workshop IARC/UCH

CANCER REGISTRIES IN NIGERIA

- Ibadan, first population-based established in Nigeria
- Zaria, Calabar, Enugu established, 1980's as hospital-based
- Ife-Ijesha, Lagos, Maiduguri,, established, 1990's, as hospital-based
- Kano, established 2000's as hospital-based
- Calabar, 2004 became population-based
- Maiduguri, 2007 became population-based
- PLAN TO RESCUSCITATE NHCRN by FMOH as part of the National Cancer Control Plan underway

WHY CANCER REGISTRATION?

Aim of establishing cancer registries:

- >To strengthen cancer statistics collection
- >To determine real incidence of cancer
- >To determine prevalence of risk factors
- >To determine cancer mortality in a population

Overall objective being for surveillance and proper planning of cancer control

CONCLUSION

- WHO encourages ALL countries to implement a national cancer control programme within a comprehensive systemic framework comprising prevention, early diagnosis, screening, curative therapy, pain relief and palliative care.
- Availability of epidemiological and pragmatic data crucial for appropriate decision-making
- Cancer Control programme for Nigeria is imperative by 2010

THANK YOU

FOR YOUR KIND ATTENTION