

CANCER IN KAMPALA: A SURVEY IN AN UNDERDEVELOPED COUNTRY

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The incidence of cancer amongst the indigenous inhabitants of the African continent has not been established in any area, and estimates have varied from the old statement of Cook (1901) that in Uganda cancer was probably as common as in England, to a recent statement by John Gunther (1955) that cancer is "almost unknown" in Africans. Reports of biopsy and necropsy studies from various parts of Africa (see Steiner, 1954) have suggested that the types and sites of cancer vary considerably in their frequency from those seen in Europe or America. The differences have not as yet been brought out clearly, but they are of general and of local importance. If differences could be clearly demonstrated they might throw light on possible environmental causes of cancer, and the information gained would be of considerable use in local diagnosis and treatment.

In 1951 the Faculty of Medicine of Makerere College set up a Cancer Research Committee to study the incidence of cancer in the local population, as it seemed possible that circumstances would be favourable to a study of this kind. This hope has been borne out by experience. As the final results of this survey will not be available for some years, and as some of the problems encountered in carrying out a cancer survey in an underdeveloped country may be of interest to others, we are publishing this preliminary report.

Kampala and its Medical Services

Kampala (altitude 4,000 ft.—1,220 metres) sited at the north-west corner of Lake Victoria just north of the Equator, is the largest town and the commercial capital of Uganda. A small island of dwellings, mostly European and Asian, together with business and industrial concerns, in a sea of freehold African land, its resident population is augmented daily by the large number of rural-dwelling Africans who cycle in to work in the town. African conurbations are of recent growth and house only a small proportion of the African population. Communication with the town by road and rail is remarkably good; a series of roads radiate outwards and a network of bus services operate from Kampala all over the country. Travel is easy, and movement of people and of goods along the roads is considerable. The wealth of Uganda is founded on its production of cotton, coffee, and tea, and, although there have been mining developments and a rapid expansion of light industries in recent years, the great majority of Africans are still rural dwellers engaged in agriculture.

The specialist medical services of the Uganda Protectorate are largely concentrated in Kampala, so that many patients are referred there from up-country hospitals in addition to the large number from near and far who attend the Kampala hospitals on their own initiative. Three of the six hospitals—Mengo, Nsamba,

and Rubaga—are run by missions; the Government operates Asian and European hospitals and Mulago Hospital, its largest institution, which is also the teaching hospital of the medical school. No private nursing-homes or hospitals exist, and there are relatively few general practitioners. The hospitals deal with all local cases of serious disease, but are also besieged by hordes of patients, whose complaints vary from the trivial to the rapidly lethal. While most of these patients are local, others may come vast distances (Monger, 1951), from ocean to ocean and from the Sahara Desert to South Africa. Hausa, Zulu, and Somali figure in the hospital records, and notable linguistic difficulties may be encountered in dealing with far-travelled patients. Pressure on beds is extreme; there are no radiotherapeutic services of any sort, and patients beyond hope of cure or relief have to be discharged to their own homes or to the care of friends. No systems of medical certification or of civil registration of death exist, or under present circumstances could exist, in the country as a whole, although in some places deaths are supposed to be recorded by the local chiefs. Nothing is known, therefore, of the mortality from cancer or from any other specific disease.

The possibility of a cancer survey in Kampala was based on the happy relationships that have existed for many years between the staffs in the Kampala hospitals. It seemed possible that with the good will and co-operation of the clinicians all cancer patients coming to the Kampala hospitals could be registered. This would at the least provide data on the relative frequency with which certain types of cancer occur in the locality, while the recording of the addresses might make it possible to calculate minimum cancer incidence rates for some areas. Such a registry would exclude an unknown number of patients who did not attend hospital, whether or not they were seen by a general practitioner.

A pilot survey carried out in 1951 had shown that very few of the out-patients suspected to be suffering from cancer were not admitted immediately, clinicians preferring to make a more careful assessment in the wards than was practicable in a crowded out-patient department. Subsequent experience has been similar. Thus, while 796 cancer patients were registered in 1952-3, only 37, 15 of them with advanced carcinoma of the uterine cervix, were seen as out-patients alone.

As it was clear from the pilot survey that a registry of in-patients would include virtually all cancer patients coming to the Kampala hospitals, it was decided to embark on a retrospective survey of the hospital records for the years 1952-3. The information thus obtained on the 796 cancer patients attending hospital was defective in many particulars; the sex was not stated in 2, the ages in 58, the tribe in 90, and the address in 68 cases. Moreover, a more serious defect was that the details could not be checked with the patients or relatives. As such a retrospective survey was unsatisfactory, with the help of the British Empire Cancer Campaign the survey was put on a current basis by the appointment of a Cancer Registrar (B.A.W.) in 1954. The cases registered in 1952-3 are, however, used in the subsequent analysis in this report, but only where the full required details were available. The analyses will therefore underestimate the true position.

Organization of the Current Survey

In view of the excessive clinical responsibilities of the hospital staffs and the lack of skilled assistance, it was unreasonable to ask them to fill in a detailed registration form. The duties of the cancer registrar include, therefore, the regular visiting of all the wards and out-patient departments of all the hospitals to obtain the required information and to ensure complete reporting. Clinicians notify cases to the registrar either directly or through sisters, nurses, or orderlies. Notification is sometimes delayed until the diagnosis is complete, but this can

have unfortunate results in that information on social details cannot then be checked with patients or relatives. For this reason early information given by sisters, orderlies, and students is very valuable. It is of no moment if patients are registered who turn out not to have malignant disease, as these can be eliminated from the records later. It is much more serious if the essential details cannot be obtained and checked with the patient or relative.

Notification cards are available in the out-patient departments—the only record required from the clinician—for details of patients seen in the out-patient department but not immediately admitted to the wards. This procedure is necessary, since some patients say they will return to the hospital after they have been home but fail to do so, while others may run away between the out-patient department and the wards.

The clinical details of registered cases are obtained from the notes in the relevant departments. In addition, completeness of registration is ensured by regular scrutiny of the histology department records, operation registers, and hospital in-patient records, and of reports submitted by the x-ray department on all tumours seen by them. This procedure was followed in 1954-5. Since 1956 an African social worker has been appointed who is directed by the registrar to interview patients. In the case of out-patients he goes immediately to the patient's home for this purpose. He fills in quite an elaborate form in which age, sex, tribe, and address are recorded, the latter in detail of site, village, county chief's name, type and construction of house, nearest important objects, and how to get to the patient's home. The names and addresses of next of kin, of children, friends, and relatives, are recorded as well as the name of the person who looks after the patient when ill at home. In recent months, where this information is available, our social worker, Mr. Y. Kayanda, has been able to obtain a 100% success in follow-up work several months later.

The information thus available could be grouped under four heads: (1) Personal details—name, age, sex, tribe, residence, next of kin, etc.; (2) registration details—hospital, year of registration, hospital number, registry number, ward, clinician, department, etc.; (3) clinical details and reports; (4) final diagnosis. Every case reported to the registry is recorded in the master register, and the information is also placed on a specially printed Copeland Chatterton analysis card. Microscopical sections, either from biopsy or necropsy, are filed in the registry.

Cases are retained only if there is satisfactory evidence of a malignant neoplastic process. Where a histological diagnosis is not available the clinical notes are individually reviewed by the Cancer Research Committee, which consists of physicians, surgeons, gynaecologists, and a radiologist, as well as pathologists. In each year the histological diagnosis rate has been over 70%, and where no such diagnosis is available clinicians often assist the committee by recording special comments. The types of case in which there is no histological confirmation vary very much. Many are hopelessly inoperable cases of carcinoma of the cervix uteri, others may have been examined radiologically, or by laparotomy, thoracotomy, or some other exploratory operation, while in others a tumour may have been viewed through some instrumental approach. Some patients absconded before they had been examined fully or before a biopsy could be made. In addition to well-recognized malignant tumours the register includes leukaemias, Hodgkin's disease, adamantinomas mixed salivary tumours, dermoid tumours, meningiomas, recurring fibromas, Kaposi sarcomas, and developmental tumours of the ovary.

Difficulties Encountered in Registering Patients

Difficulties of many kinds have been encountered in organizing the survey, many of them of a nature rarely encountered in more developed communities and nearly all

concerned with the personal details of the patients. The *name*, or the details of its spelling, may be given and recorded differently at various times, as on repeated admissions to the same hospital or on admission to different hospitals. Partial recording may cause difficulty, as when one patient attended three hospitals and was biopsied three times, once as "Kosia," once as "Kolo," and the third time as "Kosia Kolo." The patient may change his name at puberty, on marriage, or on becoming head of a family or clan. A false name may be given with the idea of warding off evil effects, or there may be a deliberate change of identity. For example, a patient in hospital gave the name of a prominent resident of her village, and on another occasion a robust individual interviewed at home claimed to be the person last seen with advanced cancer in hospital, but later admitted he was the brother who had assumed the name, house, and assets of the deceased patient.

An alphabetical or name register is therefore no safeguard against mistaken identities or against registering the same patient on several occasions. It has, however, been found useful to keep a tumour-site register separately, and this, together with close and persistent questioning, has prevented such duplication. The difficulties of this task are enhanced because in certain communities the list of names used is very restricted.

Age-recording in African patients is also very difficult, largely because until recently there was little point in an African knowing his or her age. Young people now seem to have a fairly accurate knowledge of their age, and for males the eighteenth birthday, after which they become liable for poll tax, is an obvious landmark. If the patient can be made to think it important, the age can usually be established within reasonable limits, and as an aid the committee has issued a dated list of local historical events. Despite care, however, the ages can be estimated only approximately in patients who come from far-away areas and speak languages for which it may be difficult to find an interpreter.

The *tribe* may not be recorded or stated, on the ground that it is of no importance or because the patient may wish to conceal the fact that he is not a local inhabitant. In view, however, of the many dietetic and other differences between tribes, the recording of these data is considered important.

The failure to record *addresses* accurately rendered the retrospective survey unsatisfactory, and indeed the addresses may be difficult to obtain. Some patients simply do not know where they live in a geographic sense, and for those who live in a vast, flat, sparsely inhabited and featureless area of the African bush this is understandable. They just live "over there." Usually the village—not a compact housing area but a geographical expression—the subcounty (*gombolola*) and the county (*saza*) can be recorded, especially for the local inhabitants and permanent residents. Men in particular should know the name of the chief to whom poll tax is paid; women and immigrants with no particular reason to remember the name of their locality are often vaguer about where they live. Indeed, this has sometimes to be established by finding the bus route along which they travelled to Kampala. For those who travel long distances it is sufficient to establish that they are not residents of Mengo District (see below). Some such, however, may stay in the environs of Kampala and give "accommodation" addresses. Close questioning may be necessary in order to establish the true facts, and it is often found that such persons are unlikely to be specific about the local chief's name or headquarters.

Basis for a Statistical Analysis

In 1955 one of us (J. K.) was enabled by a grant from the British Empire Cancer Campaign to visit Uganda to analyse the available material and to advise on the future programme. There were available the results of the retrospective survey of 1952-3

and of the 1954 current survey. The number of cancer cases registered in three years was very uniform, being 402, 396, and 395 respectively. The appointment of the registrar had thus not led to an increase in the number of cases registered, but it had greatly improved the quality and completeness of the information obtained.

Although patients come to the Kampala hospitals from all parts of Uganda and beyond, many from the remote areas would be treated in hospitals nearer their own homes. Consequently, patients of the Kampala hospitals cannot provide a basis for calculating incidence rates for distant areas, and it was decided to limit the analysis to residents of Mengo District, an administrative area about 100 miles (160 km.) square, with Kampala as its centre. It was hoped that reliable cancer incidence rates might be obtained for such an area.

Geography of Mengo District

Mengo District is divided into 12 sazas of varying size and population. Kampala is in the saza of Kyadondo, which extends only a few miles each side of the town but about 20 miles (32 km.) to the north. It includes both urban and rural elements, and contains the population most accessible to the Kampala hospitals. Busiro and Kyaggwe, lying west and east of Kampala respectively, are the nearest to the town except for Kyadondo. These sazas are traversed by the main trunk roads leading to Masaka and Mityana in the west and to Jinja in the east, as well as by the railways. All the other sazas are more distant and have less ready access to Kampala.

The population of Mengo District is known at present only on the basis of a complete census taken in 1948. Knowledge of the population at risk is of course fundamental to the calculation of incidence rates. The 1948 census was a more complete and detailed census of the East African population than had ever been achieved before, and we have been reliably informed that over the whole of East Africa it is believed to have been about 95% complete. Since this would include many remote and primitive areas, there is reason to believe that in the more sophisticated areas around Kampala a high standard of accuracy was obtained. Some details of the population of Mengo District have been given in a previous paper (Davies and Wilson, 1954), and much important information is given by Richards (1954), whose studies have shown that in 1948 the highest concentrations of immigrants were in plantation areas remote from Kampala. The African population of Mengo District was then just over 900,000. The age distribution of the population was recorded in groups as follows: Up to 1 year, infancy; 1-5 years, early childhood without responsibilities; 6-15 years older childhood involving share in the family tasks; 15-45 years, maturity and working age; over 45 years, dependent old age.

In this connexion it is important to note that only 11.9% of the African population of Uganda were over the age of 45 years.

Preliminary Analysis

This was limited to cases occurring in residents of Mengo District of known age and address. The cases on the register were sorted by race, age, sex, place of residence, and year of registration--1952, 1953, or 1954--after elimination of all duplicate registrations due to readmissions. There were so few cases in Asians and Europeans, or of any race under 1 year of age, that the further analysis concerned Africans only, excluding infants. Age- and sex-specific rates for the whole of Mengo District were then calculated for each year. In general, the pattern was very similar in each year, and to give greater stability to the rates the data for the three years were pooled. Further discussion is concerned with the average annual rates for the whole period

1952-4. Table I shows these age- and sex-specific rates for all cancer cases suitable for analysis in the whole of Mengo District.

TABLE I.—Average Annual Incidence Rates Per 10,000 for All Types of Cancer Among Africans in Mengo District, 1952-4

Age (Years)	Males		Females	
	Cases 1952-4	Average Annual Rate	Cases 1952-4	Average Annual Rate
1-5	6	0.39	8	0.51
6-15	20	0.69	10	0.46
16-45	201	2.40	171	2.87
Over 45	193	9.09	101	6.60

The numbers of cases were too small to calculate reliable age- and sex-specific rates for each saza. Therefore, to make regional comparisons within Mengo District, the age- and sex-specific rates for the whole area were applied in turn to the populations of each saza to calculate how many cases would be expected to be registered if reporting had been uniform throughout. The results of this analysis are summarized in Table II, which shows for Kyadondo alone, for Busiro and Kyaggwe together, and for the remaining nine sazas the number of cases registered in the three years, the number expected, and the ratio registered/expected expressed as a percentage.

TABLE II.—Relative Incidence of Cancer, All Types, Among Africans in Different Parts of Mengo District, 1952-4

Sazas	Males			Females		
	No. of cases		Reg./Exp. %	No. of cases		Reg./Exp. %
	Regis-tered	Expec-ted		Regis-tered	Expec-ted	
Kyadondo	167	64.2	260	98	41.6	236
Busiro and Kyaggwe	118	148.5	9	96	97.4	99
Other sazas	135	207.3	65	96	151.0	64
All Mengo district	420	420.0	100	290	290.0	100

For Kyadondo the incidence of cancer, based on registered cases, was over twice the average for Mengo District as a whole, with ratios registered/expected of 260% for males and 236% for females. For Busiro and Kyaggwe combined the incidence was about average for the district—ratios 79% for males and 99% for females—while the remaining nine sazas together had about two-thirds the average incidence (some had much less).

It seems unlikely that within a fairly homogeneous population there could be such large differences in the real risk of getting cancer. A more likely explanation is that there was relative under-reporting of cancer among Africans living some distance away and most complete reporting from those within easy reach of Kampala. Before such an explanation can be accepted, other possibilities have to be considered.

The first alternative explanation is that reporting was uniform throughout Mengo District but that the difference in rates was an artifact due to population changes since the 1948 census. The difference in rates could have been produced if by 1953 the population in Kyadondo had increased to about two to three times its 1948 total, the remaining saza totals being little changed. Such a selective increase could come about only by considerable immigration, principally to this one area, and no such large population movements had been recognized. The only information on population changes came indirectly from the number of poll-tax payers, males only from 18 years of age, in the area. From information generously provided by the Buganda Government it was established that by 1954 there had been an increase in the number of poll-tax payers over the 1958 figure of 39% for Kyadondo, 26% for Busiro and Kyaggwe, and 24% for the five other most populous sazas of Mengo District. Although the increase in Kyadondo was somewhat greater than elsewhere

it was much too small to account for the relative excess of cancer reported in this one saza.

A second possible explanation of the high rates for Kyadondo is that patients from more remote areas might give local accommodation addresses, such as of clan relatives, when attending hospital. A follow-up survey carried out by the medical students in 1954 had been inconclusive, except to confirm Southall and Gutkind's (1956) findings that there was considerable population mobility in the peri-urban areas of Kampala. In 1956, since the appointment of the African social worker, there has been no appreciable fall in the number of Kyadondo residents among new patients, which would suggest that "accommodation" addresses were not often given in earlier years.

A further possibility is that the rates were high in Kyadondo and low elsewhere because patients in remote sazasa suffering from cancer would go to local hospitals and would not appear in a register based on Kampala hospitals. Within Mengo District there are three local hospitals, at Bombo, Entebbe, and Mityana, which might see cancer patients. In 1952 and 1953 only 26 cases of malignant disease were reported from them, and some of these patients may have been transferred to Kampala. Outside Mengo District the hospital at Jinja, just beyond the eastern boundary, might drain some patients, but a search of the operation records revealed only 16 possible malignant conditions in a period of nine months. The hospital at Masaka, on a trunk road 80 miles (130 km.) from Kampala, is too far to take Mengo District residents except a few from the thinly populated south-western part, and the remaining Uganda hospitals are still further away. The number of cancer patients attending local hospitals is therefore so small by comparison with those seen in Kampala hospitals that even if they were included in the register they would have little effect on the incidence rates for the different sazasa.

We are left with the explanation that people living in remote areas are less likely to attend any hospital than those living near Kampala, and that incidences for such sazasa based on hospital experience will be gross underestimates. For Kyadondo itself the rates should be a far better measure of the real risk, though any error is likely to be towards under- rather than overestimation. Such an explanation of the higher rates in Kyadondo is confirmed by an analysis of the site distribution of registered cases. The proportion with more superficial or easily diagnosable cancers, such as skin and penis in the male, skin and breast in the female, was greater in those from sazasa other than Kyadondo, while the proportion with the more obscure internal cancers—for example, those involving the liver and lymphatic glands—was greater in Kyadondo patients. These site differences were not produced by selective transfer from local to Kampala hospitals of cases amenable to surgery.

**Comparison of Kyadondo and Danish Cancer Incidence
Total Cancer Incidence**

This preliminary analysis of the Kampala Registry findings for Kyadondo has been compared with the results of the Danish Cancer Registry for 1942-4 (Clemmesen, 1955) in Table III. The age groups used in the two surveys are not identical, but the more numerous groups of the Danish material were amalgamated to bring them as near as possible to the Kyadondo data. The Danish population was obviously older than that of Kyadondo, so that over 45 years of age the rates would not be comparable, but as a rough approximation the Danish rate for 45-54 years is given alongside the Kyadondo at over 45 years in Table III.

The Kyadondo rates were in general of the same order as those in Denmark throughout the age groups shown. The chief exception to this was that women over 45 years of age in Kyadondo had less than half the cancer incidence of Danish women 45-54 years of age. The corresponding rates for men were very similar. The choice of the Danish 45-54 year group as

a proper comparison for the Kyadondo women over 45 may well be wrong, as some individual Africans were aged 70 or more, but any adjustment in this figure would only increase the differences between the two studies. On the other hand, the rate for Danish women aged 35-44 years--17.3 per 10,000-- was slightly greater than the rate for Kyadondo women over 45. Since the reluctance of the older women to attend hospital is well recognized in Kampala, some degree of under-reporting in this group is to be expected.

TABLE III.—Comparison of Incidence Rates for All Malignant Tumours in Kyadondo, 1952-4, and in Denmark, 1942-4 (Average Annual Rates Per 10,000)

Kyadondo, 1952-4			Denmark, 1942-4		
Age	Rate		Age	Rate	
	Males	Females		Males	Females
1-5 years	0-5	1-6	0-4 years	1-62	1-08
6-15 "	2-7	0-3	5-14 "	0-85	0-64
16-45 "	6-0	7-0	15-44 "	4-43	8-19
46+ "	24-3	15-3	45-54 "	22-57	35-72

Site Differences

Particular interest lies in the incidence rates for individual sites. It is clear that in Kyadondo these show outstanding differences from the experience of highly developed communities, although the overall rates for all sites combined may be of the same order. In Table IV a comparison between the incidence of cancer of certain selected sites in Kyadondo and Denmark is shown. For this table the Danish rates for ages 15-44 were applied to the Kyadondo population 16-45 years of age, and the Danish rates at 45-54 years were applied to the Kyadondo population over 45 years of age to obtain the number of "expected" cases. The actual cases registered among Africans over 15 years of age can then be compared directly with these expected numbers.

From this provisional analysis a number of striking discrepancies appear--the excess of liver cancer in Kyadondo men but not in the women, and the excess of penile and, to a less extent, lymphatic tumours in men. The deficiency of cancer of the gastro-intestinal tract in both sexes is clear, and breast carcinoma of women in Kyadondo was also reported less frequently than in Denmark. The figures given in Table IV may obscure some differences. For example, the total incidence of kidney and bladder tumours may appear to have been of the same order in Kyadondo as in Denmark, but this is largely because a deficiency in the renal carcinoma in Kyadondo was counterbalanced by a great excess of Wilms's tumour.

TABLE IV.—Comparison of Incidence of Cancer of Selected Sites in Kyadondo, 1952-4, With that Expected at Danish Rates, 1942-4

Site	Males		Females	
	Registered Cases	Expected Cases	Registered Cases	Expected Cases
Skin	14	10-5	4	5-9
Gastro-intestinal	18	35-4	10	20-1
Liver	26	2-0	2	1-9
Kidney, bladder, etc.	19	13-1	2	2-0
Penis	11	1-2	--	--
Breast	--	--	9	30-7
Ovary and tubes	--	--	12	10-6
Uterus	--	--	28	43-5
Lymphatic system	22	10-2	4	5-4

Too much emphasis should not be placed on these comparisons, and judgment should await the large experience it

is hoped to accumulate from the Kampala registry. Nevertheless, the preliminary conclusions reached are that, for certain age groups at least, the total incidence of cancer in Kyadondo is similar to that in Denmark, but that there appear to be remarkable site differences.

Future of the Kampala Survey

In recent years this survey has been generously supported by an annual grant from the British Empire Cancer Campaign. It is hoped to continue the survey for at least one year after the conclusion of the next complete census, which is planned for 1958. It is also hoped to continue till the number of cases is sufficient to enable any differences in the incidence of the less common tumours to be explored. The indications are that some striking differences will be found in the incidence of certain less common tumours, such as Kaposi sarcoma, granulo-cell tumours, and chorionepithelioma. When the census returns are available it should be possible to publish a full and detailed report which will enable valid comparisons to be made with other areas.

If the differences which it is believed will be shown up are confirmed, the task will be to explain these differences. This may need much more exploration of the social, economic, and medical backgrounds of the Kampala cases than we are attempting at present. It has been suggested that some of this work should be put in hand now. For a number of reasons the Cancer Research Committee has been reluctant to embark on such activities. Firstly, it has considered that its main task is to establish the cancer incidence figures in Kyadondo as accurately as possible, and other aims have been temporarily subordinated to this. This in itself put a considerable strain on the limited staff available, and any extension might prejudice the good will and co-operation of the Kampala clinicians which has been so generously afforded to the Research Committee. Further, the collection of data on the social and environmental background of cancer patients alone might be of little use because of the lack of similar information on Africans not suffering from cancer with which it could be compared. For these reasons the committee declined to consider suggestions for broadening the scope of its survey until its primary aims are achieved.

It does, however, feel confident, as a result of its experience, that a cancer survey of the type carried out is promising and worth while in an area in which it might superficially appear to be worthless and unrewarding. Granted the co-operation of clinicians, accurate recording of cases and pertinent data, and a knowledge of the populations at risk, and particularly with the accurate recording of the addresses, cancer surveys can be carried out in underdeveloped and underdoctored areas.

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