Chapter 8

Cancer survival in Cuba

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Introduction

Cuba is the biggest island of the Caribbean archipelago with an area of 114 524 km^2 (Fig. 1) and 11 million inhabitants in 1995, with a sex ratio of 988 females to 1000 males. The structure of the population is shown in Fig. 2. Less than one-quarter of the population is under 15 years of age and those aged 65 and over constitute just over 8%. The country is divided into 14 provinces. It has a unique national health care system emphasizing primary health and medical care, which is readily accessible to the population throughout the country. Cuba is one of the very few developing countries to have a reliable nationwide death registration system. In this chapter, we discuss survival from selected cancers in Cuba in the context of background information on cancer registration and health services in the country.

Cancer registration in Cuba

The National Registry of Cuba was established in 1964 within the framework of the national health system of Cuba. Its objectives are to describe the annual cancer burden in terms of incidence and mortality, to conduct epidemiological cancer studies and to monitor and evaluate cancer control activities. Until 1986, the registry relied on voluntary reporting of cases and notifications from the death registration system. The Ministry of Public Health of the Cuban Government then made it compulsory for all secondary health facilities and physicians to report cases to the registry.

Figure 1. Map showing location of Cuba

As already indicated, data collection is passive. The National Registry of Cuba receives information from two major sources: (1) hospitals and (2) death certificates through the National Statistics Directorate. The difficulty of tracing back a large number of death certificate notifications (DCN) has been a persistent problem in the registry, and hence many DCNs ended up as 'death certificate only' (DCO) registrations. Since 1995, efforts have been made to trace the relevant information.

The central office of the National Registry of Cuba is located at the National Institute of Oncology and Radiobiology, Havana, which is the coordinating body for cancer control in Cuba. Until 1991, hospital reports were collected by the provincial health offices and then sent to the registry's central office for processing. Since 1992, provincial cancer registries have been introduced, in which the information reported from the hospitals of the province is entered into the computer and checked for consistency, and duplicates are eliminated. The data are then sent to the central office, where they undergo consistency checking, duplicate checking and coding. The primary site and morphology of the cancers are coded using the *International Classification of Diseases for Oncology*, First Edition (ICD-O) (WHO, 1976). The topography is converted to *International Classification of Diseases, Ninth Revision* (ICD-9) codes for reporting purposes (WHO, 1978).

For several years, the National Registry of Cuba has published annual reports containing a detailed analysis of incident cases. Data on cancer incidence from the registry for the periods 1968-72 and 1973-77 and the year 1986 were included in Volumes III and

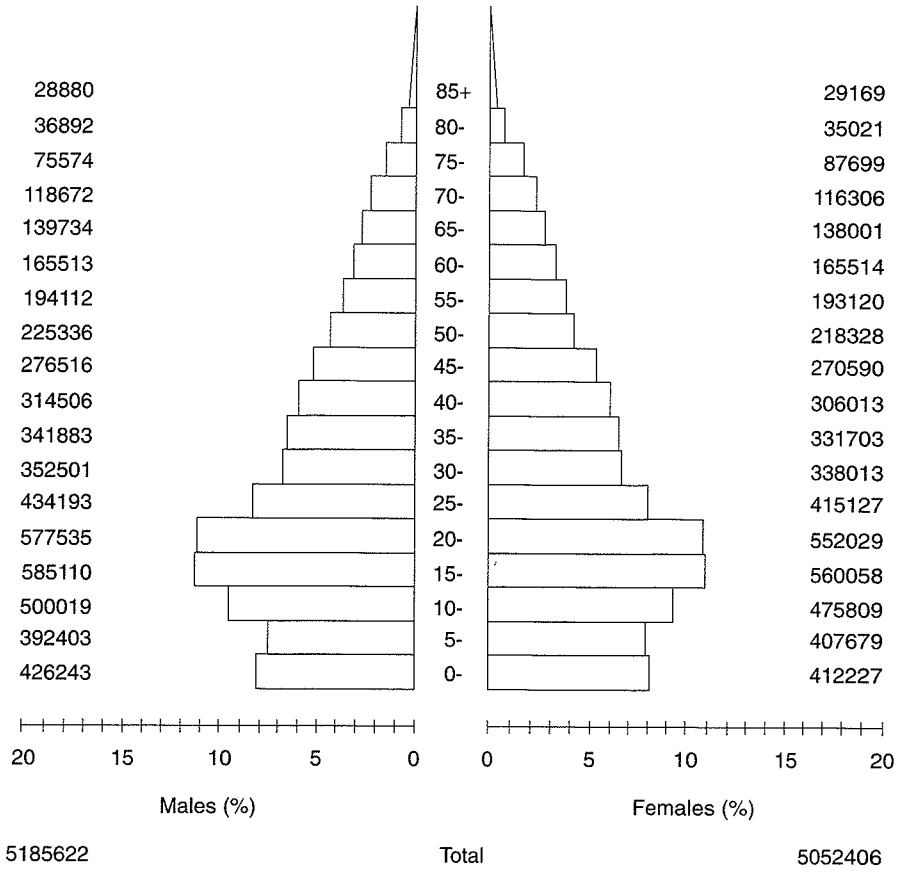

Figure 2. Average annual population of Cuba, 1986

IV (Waterhouse *et al.*, 1976, 1982) and VI (Parkin *et al.* 1992) of *Cancer Incidence in Five Continents*. Mortality data from Cuba have been used to study cancer trends (Coleman *et al.*, 1993). A survival study has also been reported using an earlier series of cases registered by the National Registry of Cuba (Graupera *et al.*, 1994).

Cancer incidence in Cuba

The number of cancer cases, crude and age-standardized incidence rates for males and females in 1986 are given in Table 1 (Parkin *et al.*, 1992). In men, the most common cancers are lung (20.5%), non-melanoma skin cancers (14.9%), prostate (14.0%), stomach (4.6%), bladder (4.5%), larynx (4.4%) and colon (4.4%). These seven cancer sites constitute more than two-thirds of all male cancers. Among females, the breast was the most common cancer site (17.9%) followed by non-melanoma skin cancer (12.9%) and cancers of the uterine cervix (10.2%), lung (8.6%) and colon (5.7%). These cancers account for more than half of all female cancers. There has been an increasing trend in the occurrence of lung and breast cancers.

Cancer health services

Cuba has developed a public health care system based on extended primary care and equality of access. At the community level, there is a family physician, supported by a nurse, for every 800 people and a dentist for every 1000 people. These medical staff live among the population they serve, providing basic health care. The general hospital services have been developed to cater for the need for specialized care for people referred from the primary health care services. Cancer diagnostic services and surgery are widely available throughout the country, with a total of 984 oncology beds and 162 specialists in oncology. Three comprehensive cancer centres located in three provinces (Havana City, Camagüey and Santiago de Cuba) provide specialized diagnostic facilities, radiotherapy and chemotherapy. Twelve general

hospitals provide oncology services (five in Havana City, two in Granma and one each in Matanzas, Sancti-Spiritus, Ciego de Avila, Las Tunas and Guantánamo). Overall, there are 23 chemotherapy, 11 radiotherapy and eight paediatric oncology services throughout the country to facilitate the population's access to health services.

Cancer control programme

In Cuba, a comprehensive national cancer control programme was set up in 1987, with activities in prevention (anti-smoking programme), early diagnosis, screening, oncopaediatric health care and public health education.

Since 1968, a cervical cancer screening programme with cytology screening has been provided for sexually active women aged 20 years or over. Cytology is offered at two-year intervals. Just over one million smears are performed annually, and are processed in thirty regional cytology laboratories. More than 80% of women have been screened at least once. However, the incidence of and mortality from cervical cancer have not decreased since the introduction of the screening programme (Coleman *et al.*, 1993; Fernandez Garrote *et al.*, 1996; Sankaranarayanan & Pisani, 1997). On the contrary, small increases in incidence and mortality have been observed, particularly among young women. A recent evaluation stated that low coverage of high-risk groups and poor quality of cytology (taking, processing and reading smears) are probably responsible for the programme's lack of impact (Fernandez Garrote *et al.*, 1996). Since 1997, the programme has covered women aged between 25 and 59 years, concentrating on women aged 35 or over, and the interval between screenings has been increased to three years.

An early detection programme for breast cancer was implemented in 1989. The objectives were to teach breast self-examination to all women aged 30 years or over, as well as encouraging them to have their breasts examined annually by their family physician. It had been intended to offer mammography once every two years to women aged 50–64 years, but economic difficulties have meant that this has not been done. Over the last six years, 452 508 women have been invited for mammography, of whom 211 258 (47%) complied, and 542 breast cancers have been detected.

An oral cancer screening programme was introduced in 1984, which required dentists to offer an annual visual inspection to all subjects aged 15 years and over to detect oral precancers and cancers (Fernandez Garrote *et al.*, 1995). During the period 1984–90, 13 million examinations were carried out and 30 244 subjects with lesions were identified; however, the annual participation rate of the population and compliance with referral was only 28.8%. No reductions in incidence or mortality have been observed so far. At present, the target group for the programme is people aged 35 years and over.

A pain relief and palliative care programme is being developed and extended throughout the country. Hepatitis B vaccination is offered to high-risk population groups and to all neonates routinely as part of the extended immunization protocol.

There are active health education programmes to promote awareness of cancer risk factors and to encourage people with risk factors to remain vigilant in order to promote early detection of cancers.

Survival analysis

Subjects and methods

The cancer sites considered for the survival analysis were the tongue, oral cavity, oropharynx, colorectum, lung, female breast, cervix, corpus uteri, ovary and prostate, as well as lymphoid and haemopoietic malignancies. The total number of cases registered, the proportion of DCO registrations (which are mostly DCNs), the proportion with histological verification, and the number and proportion of cases included in the final survival analysis for these cancers are shown in Table 2.

We made an attempt to trace back the DCN cases in 1994 and 1995 after we began the survival study. We could trace back only 12% of DCO registrations in 1988 and 17% of those in 1989 (a total of 2570 cases). In Cuba, hospital medical records departments are not allowed to retain the clinical records of deceased persons for more than five years. For this reason, the records of many DCN registrations from 1988 and 1989 could not be traced.

A total of 24 601 cases were registered during 1988–89 for the sites considered for analysis. Of these 8 892 cases (36.1%) were based on DCNs and could not be traced back retrospectively in 1994–95. We have excluded all these cases. The other excluded cases were those with no follow-up information (N=2905, 11.8%) and eight cases with no information about the person's age. Thus a total of 11 805 (48.0%) cases were excluded and this left 12 796 cases (52.0% of the incident cases) for final analysis. The proportion of cases included in the final survival analysis varied from 36.5% for multiple myeloma to 74% for cervical cancer.

Table 1. Average annual cancer incidence per 100 000 person-years in Cuba, 1986

Site	MALES			FEMALES		
	Number	Crude rate	ASR	Number	Crude rate	ASR
Lip	138	2.7	2.6	22	0.4	0.4
Tongue	129	2.5	2.4	58	1.1	1.1
Salivary gland	41	0.8	0.8	24	0.5	0.4
Mouth	133	2.6	2.4	74	1.5	1.3
Oropharynx	97	1.9	1.8	20	0.4	0.4
Nasopharynx	35	0.7	0.7	16	0.3	0.3
Hypopharynx	47	0.9	0.9	11	0.2	0.2
Oesophagus	290	5.6	5.2	97	1.9	1.7
Stomach	562	10.9	9.8	278	5.5	5.0
Colon	533	10.3	9.4	572	11.2	10.2
Rectum	243	4.7	4.3	240	4.7	4.3
Liver	208	4.0	3.6	203	4.0	3.6
Gallbladder	90	1.7	1.6	146	2.9	2.7
Pancreas	308	6.0	5.4	222	4.4	3.8
Larynx	539	10.4	10.2	115	2.3	2.2
Lung	2499	48.4	44.3	861	16.9	15.7
Bone	106	2.1	1.9	69	1.4	1.3
Connective tissue	81	1.6	1.4	96	1.9	1.8
Melanoma of skin	63	1.2	1.2	47	0.9	0.9
Other skin	1816	35.2	33.2	1290	25.4	23.6
Breast	12	0.2	0.2	1787	35.1	35.0
Cervix uteri				1019	20.0	20.0
Corpus uteri				294	5.8	5.7
Ovary				294	5.8	5.7
Prostate	1714	33.2	27.3			
Testis	33	0.6	0.6			
Penis	102	2.0	1.9			
Bladder	555	10.8	9.7	159	3.1	2.8
Kidney	114	2.2	2.2	67	1.3	1.3
Brain	222	4.3	4.4	178	3.5	3.6
Thyroid	61	1.2	1.1	190	3.7	3.6
Hodgkin's disease	82	1.6	1.5	147	2.9	2.8
Non-Hodgkin lymphoma	171	3.3	3.3	201	4.0	3.9
Multiple myeloma	108	2.1	1.9	139	2.7	2.5
Lymphoid leukaemia	97	1.9	2.0	139	2.7	2.6
Myeloid leukaemia	137	2.7	2.5	141	2.8	2.6
All sites	12207	236.5	217.2	9964	195.9	187.2
All sites except skin	10391	201.3	184.0	8674	170.6	163.6

ASR: Age standardized incidence rate (world population)

Follow-up

In order to establish the vital status (alive/dead) of the cases up to the closing date of 31 December 1994, a mixed (passive and active) follow-up system was used. Incidence data files were matched with the files of the National Mortality Registry for 1988–94 to identify people who had died and establish their date and cause of death. A computerized record linkage procedure was used for this purpose. The remaining cases were then matched with the files of the National Identity Registry (a repository of citizens' names and identity numbers) by manual matching of the provincial, alphabetically arranged 'apparently alive cases' with the lists of subjects maintained in the provincial offices of the National Identity Registry. Other active follow-up methods

were used to establish the vital status of people whose outcome could not be ascertained by the above methods, e.g. reply-paid postal enquiries were sent to their homes and employers. The vital status of the remaining cases was checked at their hospital of attendance, using the clinical record as the source.

Of the 12 796 cases included in the study, definite information about the vital status of 12 109 cases (94.6%) was available at the closing date. The rest (5.4%) were lost to follow-up prior to that; 3% at less than one year, 1.9% at 1–4 years and 0.5% five years or more from the date of diagnosis of cancer.

Analytical methodology (see Chapters 2, 3 and 5)

The index date for calculation of survival time was the incidence date. The survival time for each case was the time between the index date and the date of death *or* date of loss to follow-up *or* 31 December 1994. Cumulative observed and relative survival rates were calculated by Hakulinen's method (Hakulinen, 1982; Hakulinen *et al.*, 1994). The expected survival rate for a group of people in the general population similar to the patient population with respect to age, sex, and calendar period of observation was calculated using the national life tables for 1988–91 (National Statistics Office, 1995). Age-standardized relative survival (ASRS) was calculated for all ages and for the age group 0–74 years by directly standardizing the site-specific and age-specific relative survival to the site-specific age distributions of the estimated global incidence of major cancers in 1985, to facilitate comparison with survival results from other countries.

Results

The site-specific cumulative one-year, three-year and five-year observed and relative survival rates for both sexes combined and five-year survival by sex are shown in Table 3. A five-year relative survival in excess of 60% was observed for cancers of the breast and corpus uteri. Survival was less than 20% in lung cancer, multiple myeloma and myeloid leukaemia. Females had a notably higher survival rate than males in tongue, oral cavity and colon cancers. The differences were minimal for lymphomas and lymphatic leukaemia. The site-specific and age-specific number of cases and five-year relative survival, ASRS for all ages and ASRS in the age group 0–74 are shown in Table 4. Survival was generally higher in younger age groups, especially for cervical cancer and lymphomas. An increasing five-year relative survival with increasing age occurred in prostate cancer.

The five-year observed survival by clinical extent of disease for selected sites is shown in Table 5 and Figs. 3–8. Five-year observed survival rates indicate comparatively higher survival rates for localized cancers, particularly in the breast and cervix. This indicates that the information collected about extent of disease is valid and reflects the range of survival experience in early and advanced cancers to a certain extent. An inverse relationship between the extent of disease and survival is clearly seen.

Discussion

A major limitation of our study is the large proportion of DCO registrations, which were excluded from the analysis. There is justifiable concern about the quality of our data and the effects this may have had on our results. However, the plausible results obtained in the case of cancer sites included in the analysis indicate that the exclusions may not have resulted in a serious degree of selection bias. We believe that the cases selected for analysis represent a reasonable sample of all persons with cancer. The excluded cases represented a sample of all the registered cases and are unlikely exclusively or predominantly to represent cancers with a poor prognosis.

In most cancer registry settings, the DCO cases are most likely to be people with cancers with aggressive natural histories, elderly people and those of low social status who could not obtain adequate treatment when they were alive. However, this does not seem to be the case with our data from Cuba. If it were, we would have seen highly inflated survival rates. This conclusion is also supported by the results of an analysis of traced-back DCNs. Measures are now being implemented to improve coverage by registering patients soon after they are diagnosed and tracing patient records promptly after death certificate notifications. This will improve cancer registration in Cuba in the future.

In spite of Cuba's well organized health services, the impact of intervention programmes could not be measured satisfactorily from cancer registration and mortality data, owing to problems of documentation and information processing. The survival investigation is very important in this context and emphasizes the need to consider ways in which our information systems can be reorganized for valid evaluation of services. Even with their limitations, the data presented here reveal the importance of early detection in improving prognosis in cancers of the oral cavity, colorectum, breast and cervix.

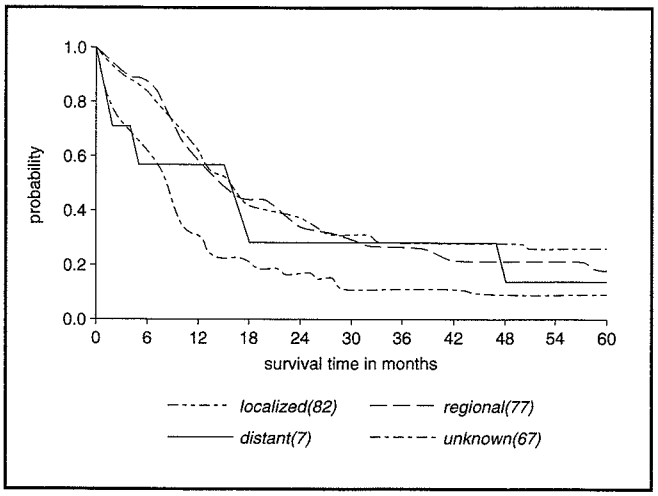

Figure 3. Survival from tongue cancer by clinical extent of disease in Cuba

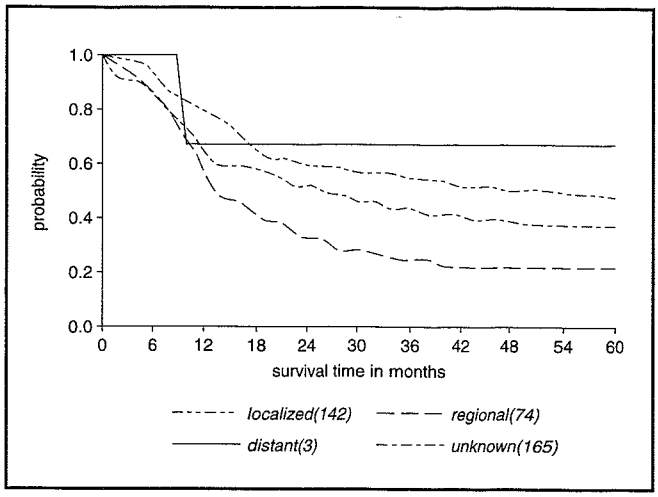

Figure 4. Survival from oral cavity cancer by clinical extent of disease in Cuba

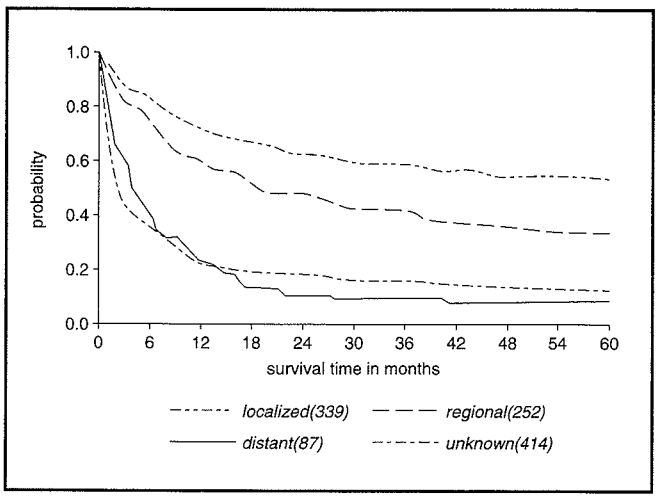

Figure 5. Survival from colon cancer by clinical extent of disease in Cuba

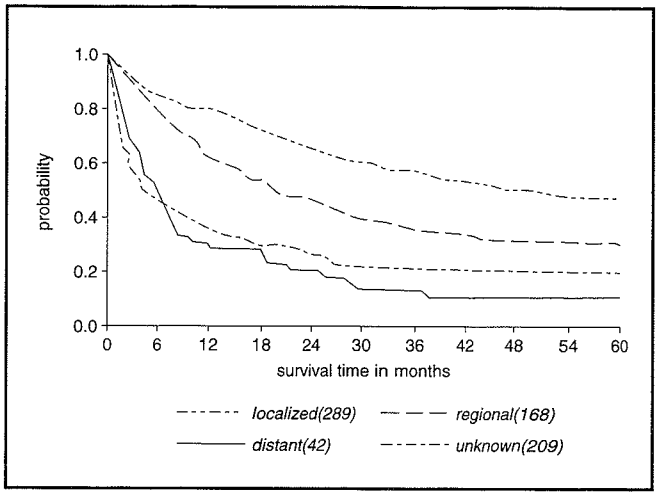

Figure 6. Survival from rectum cancer by clinical extent of disease in Cuba

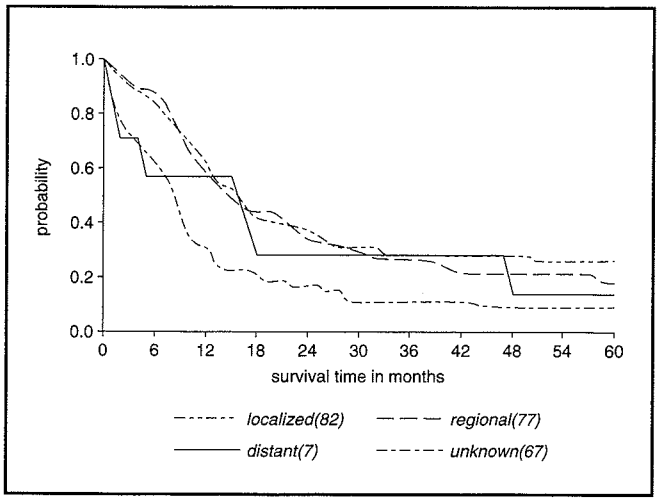

Figure 7. Survival from breast cancer by clinical extent of disease in Cuba

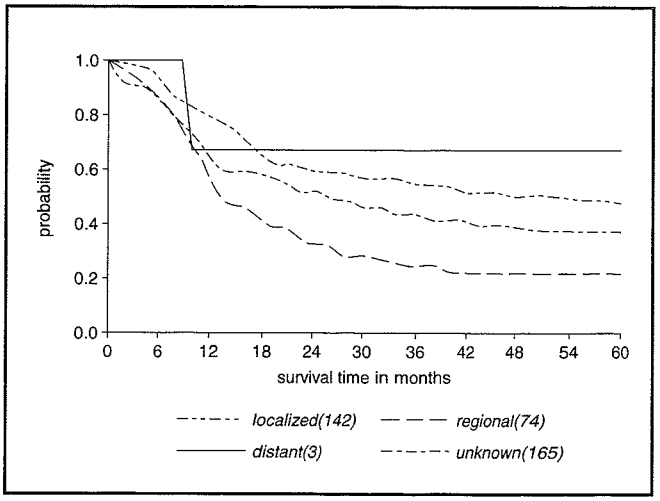

Figure 8. Survival from cervical cancer by clinical extent of disease in Cuba

Table 2. Cases of cancer registered and data quality indices, Cuba, 1988–89

Site	ICD 9	No. of cases registered	Data quality indices		Cases excluded from analysis		Cases included for survival analysis	
			% DCO	% HV	DCO	Others	No.	%
Tongue	141	341	21.7	75.1	74	34	233	68.3
Oral cavity	143–5	542	12.2	82.7	66	92	384	70.8
Oropharynx	146	178	18.5	76.4	33	34	111	62.4
Colon	153	2381	45.7	44.1	1089	200	1092	45.9
Rectum	154	1098	22.6	71.1	248	142	708	64.5
Colorectum	153–4	3479	38.4	52.6	1337	342	1800	51.7
Lung	162	6896	52.2	28.0	3597	520	2779	40.3
Breast	174	3501	19.1	73.8	668	458	2375	67.8
Cervix	180	2059	8.5	89.0	176	352	1531	74.4
Corpus uteri	182	553	8.3	88.6	46	105	402	72.7
Ovary	183	593	24.1	70.5	143	94	356	60.0
Prostate	185	3494	46.2	48.6	1614	484	1396	40.0
Hodgkin's lymphoma	201	465	26.5	73.5	123	58	284	61.1
Non-Hodgkin lymphoma	200,202	871	32.0	68.0	279	127	465	53.4
Multiple myeloma	203	480	50.4	49.6	242	63	175	36.5
Lymphatic leukaemia	204	455	34.3	65.5	156	77	222	48.8
Myeloid leukaemia	205	497	44.1	55.9	219	52	226	45.5
All leukaemia	204–8	1149	43.0	56.9	494	150	505	44.0

DCO : Death certificate only; HV : Histological verification

Implications

The major implication of this study is to show the need for a rapid improvement in coverage and the introduction of a systematic follow-up of cases, which would strengthen health information systems for a valid evaluation of cancer control measures. The existing early detection programmes also need to be made more effective. These are urgent requirements if we are to take advantage of the well developed diagnostic and therapeutic infrastructure of Cuba and sustain the progress already achieved in public health.

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Table 3. Observed and relative survival by site and sex in Cuba, 1988-89

Site	ICD 9	Number included	All ages and both sexes combined: Observed survival (OS) 1 yr	OS 3 yr	OS 5 yr	Relative survival (RS) 1 yr	RS 3 yr	RS 5 yr	% survival rate at 5 years by sex: Male Number	Male OS	Male RS	Female Number	Female OS	Female RS
Tongue	141	233	52.3	23.1	19.0	56.6	27.9	25.5	172	15.8	21.8	61	28.2	35.1
Oral cavity	143–5	384	69.2	44.0	38.5	71.6	51.7	49.1	272	36.1	45.8	112	44.4	56.9
Oropharynx	146	111	65.3	31.9	27.0	70.8	37.3	33.7	89	28.7	36.3	22	19.8	23.6
Colon	153	1092	47.2	35.1	29.2	51.4	41.7	38.1	475	25.6	34.2	617	31.9	41.0
Rectum	154	708	59.5	38.2	31.7	64.8	45.6	41.7	354	30.1	40.7	354	33.4	42.6
Colorectum	153–4	1800	52.0	36.4	30.2	56.7	43.3	39.5	829	27.5	36.9	971	32.5	41.6
Lung	162	2779	23.7	10.6	8.4	25.5	12.4	10.7	2083	7.7	10.0	696	10.4	12.6
Breast	174	2375	81.1	64.6	54.0	83.8	69.5	60.8				2375	54.0	60.8
Cervix	180	1531	75.7	57.1	52.3	77.0	59.4	55.9				1531	52.3	55.9
Corpus uteri	182	402	78.4	59.3	51.7	81.6	65.5	60.9				402	51.7	60.9
Ovary	183	356	55.0	42.4	39.3	56.8	45.5	43.3				356	39.3	43.3
Prostate	185	1396	62.4	40.4	27.0	73.1	55.7	45.1	1396	27.0	45.1			
Hodgkin's lymphoma	201	284	70.3	58.5	51.0	71.9	61.2	54.9	167	50.4	54.0	117	51.9	56.2
Non-Hodgkin lymphoma	200,202	465	54.7	37.2	31.8	57.0	40.6	37.0	274	30.6	35.6	191	33.7	39.0
Multiple myeloma	203	175	40.1	21.5	14.9	41.8	23.8	17.9	104	13.7	16.7	71	17.0	19.8
Lymphatic leukaemia	204	222	49.0	33.1	27.0	51.0	36.0	30.7	137	25.6	29.1	85	29.1	33.4
Myeloid leukaemia	205	226	33.2	16.4	10.2	34.1	17.8	11.6	129	14.0	15.8	97	5.2	6.0
All leukaemia	204–8	505	40.0	24.2	18.5	41.5	26.6	21.3	299	19.3	22.3	206	17.3	20.0

Table 4. Site-specific and age-specific number of cases, five-year relative survival and ASRS in Cuba, 1988–89

Site	ICD 9	Number of cases by age group ≤34	35–44	45–54	55–64	65–74	75+	% Relative survival (RS) at 5 years ≤34	35–44	45–54	55–64	65–74	75+	RS All ages	ASRS% All ages	ASRS% 0–74
Tongue	141	3	9	25	59	69	68	67.2	11.3	28.9	22.7	15.0	53.4	25.5	30.8	25.0
Oral cavity	143–5	9	18	60	83	120	94	52.9	36.1	41.9	38.7	47.0	91.6	49.1	52.4	42.4
Oropharynx	146	1	6	22	28	32	22	101.1	16.9	37.5	23.3	43.0	32.4	33.7	30.4	29.9
Colon	153	35	46	142	233	324	312	39.1	42.9	30.9	35.6	35.8	54.3	38.1	43.3	35.7
Rectum	154	14	36	85	157	199	217	36.0	33.0	34.0	43.8	41.5	50.1	41.7	43.9	39.7
Colorectum	153–4	49	82	227	390	523	529	38.3	38.6	32.1	38.9	37.9	52.6	39.5	43.5	37.2
Lung	162	27	175	387	637	849	704	26.0	12.0	13.2	7.9	9.0	15.2	10.7	11.8	10.2
Breast	174	100	400	591	553	441	290	53.7	62.1	57.9	55.7	58.7	104.0	60.8	67.2	57.9
Cervix	180	217	408	366	270	174	96	66.0	60.8	53.4	54.1	40.2	47.7	55.9	53.5	54.3
Corpus uteri	182	9	28	67	119	102	77	78.3	73.6	54.6	56.0	57.2	83.4	60.9	63.9	58.7
Ovary	183	45	51	80	85	64	31	60.3	46.8	42.0	26.2	41.4	92.5	43.3	50.1	41.1
Prostate	185	0	5	38	161	478	714	–	20.4	22.9	31.9	39.7	64.4	45.1	54.9	35.9
Hodgkin's lymphoma	201	136	38	33	38	19	20	63.8	65.5	61.0	29.1	6.3	46.8	54.9	54.3	54.8
Non-Hodgkin lymphoma	200,202	99	52	58	87	94	75	37.9	49.9	40.4	42.3	22.1	26.8	37.0	35.0	37.4
Multiple myeloma	203	0	8	24	50	56	37	–	12.7	22.8	8.6	22.9	24.3	17.9	14.9	12.2
Lymphatic leukaemia	204	104	11	13	28	36	30	38.8	39.5	7.9	39.3	13.4	8.1	30.7	26.6	31.1
Myeloid leukaemia	205	76	22	22	31	41	34	10.6	13.8	14.1	17.4	5.7	13.0	11.6	11.4	11.6
All leukaemia	204–8	200	39	37	62	91	76	27.0	20.1	11.2	25.8	9.4	19.8	21.3	21.0	21.3

– No cases; ASRS: Age-standardized relative survival

Table 5. Five-year observed survival by clinical extent of disease selected cancers in Cuba, 1988-89

	Clinical extent of disease classification			
Site	**Localized**	**Regional**	**Distant**	**Unknown**
Tongue	26.8	18.9	14.3	9.7
Oral cavity	47.8	22.0	66.7	37.7
Colon	52.4	33.0	8.4	12.1
Rectum	46.2	28.7	9.6	18.4
Breast	70.9	46.4	20.4	44.1
Cervix	70.9	34.2	24.2	41.0

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