

The Estimation of Cancer Incidence in Aichi Prefecture, Japan: Use of 'Degree of Completeness of Registration'

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This study was conducted to estimate true incidence of the total number of cancer cases and of cancers at selected sites in the population of Aichi Prefecture, Japan, using the degree of completeness of registration (CR). Information on incidence (I), death (D), and cases first notified via death certificate (DCN) was based on the data from 1976 to 1993. Using this information, CR for each cancer site was calculated by gender and a 3-year period of diagnosis [$CR = (1 - PDCN \cdot I/D) / (1 - PDCN)$, PDCN: proportion of DCN cases]. The true number of incident cases and incidence rates (estimated incidence rate: EIR) were then estimated from the number of cases observed and from CR. CR for all sites of cancer was 62-78 percent in males and 54-72 percent in females, and CR was higher in cancers with low I/D ratios than those with high I/D ratios. Annually, about 2,500-3,000 cases in each gender were unreported. The EIR of all sites was estimated at 252-280 in males and 213-207 in females compared with the incidence rates observed (observed incidence rate: OIR) as 157.0-218.6 in males and 115.3-149.2 in females. OIR was closer to the EIR for cancers with low I/D ratios than those with high I/D ratios. These values are important for planning and evaluating cancer control strategies in the population. *J Epidemiol*, 1998 ; 8 : 60-64.

cancer incidence, cancer registry, DCN, completeness of registration

Population-based cancer registration has been the only way to obtain information on cancer incidence on a population basis, and thus it plays a crucial role in cancer control. The operation of population-based cancer registries varies according to population size, funds and manpower available for operating the registries, and local laws and regulations. These factors affect the quality of the registered data, although it is obviously desirable that the registration of cancer cases be as complete as possible¹⁾.

In Japan, population-based cancer registries are organized by local governments and not the national government. Aichi Cancer Registry was established in 1962 as a population-based cancer registry. The population of Aichi Prefecture was estimated at 6.9 million in 1995, therefore this registry covers one of the largest population sizes in Japan, and, indeed in the world. However, due to the large population and lack of man-

power, its quality has not reached the level required internationally. Thus, it has been suggested that the incidences estimated by the sum of registered cases and cases first notified via death certificate (DCN) are relatively low, compared with those produced by other reliable registries. For such registries with insufficient quality, some method of estimating the true incidence rate is needed.

Completeness of cancer registration (CR) is defined as the extent to which all the incident cancers occurring in a target population are included in the registry data²⁾. There are various methods of evaluating CR, including cases with death certificate only (DCO), DCN, ratio of incident cases to deaths (I/D ratio), and so forth. Previous studies have assessed several methods to estimate CR, using DCN as a measure of completeness³⁾, capture-recapture method⁴⁾, and comparison of methods above⁵⁾. Other studies have tried to estimate cancer incidence

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using indicator of the completeness such as trace-back cases ^{6,7}, DCO and I/D ratio ^{8,9}.

The proportion of DCN cases is regarded as an indicator of CR. DCN cases are detected first when death certificates are matched with registry case files. After these cases have been traced back, and those generating further information from hospitals or physicians which is sufficiently strong as to warrant registration has been excluded, the residue of cases, with no information other than death certificates are registered as DCO. When DCN cases are not traced back, DCN and DCO cases coincide. When they are traced back, DCN cases exceed DCO cases, as they form the subgroup of DCN cases with information gathered in the trace-back.

Information on the proportion of DCN cases enables us to calculate CR^{2,3}. CR, here, is defined as the proportion of the observed incident cases (the sum of registered cases and DCN cases) among the true number of incident cancer cases in the population. Theoretically, it is possible to estimate the true incidence by knowing the observed incidence and CR. However, estimation by this method has not been conducted previously in Japan. In Aichi Prefecture, the proportion of DCN cases for each cancer site has been available for every year since 1976, and this enabled us to estimate the true incidence. The present study, thus, tries to estimate the true incidence of the total number of cancer cases and cancers at selected sites, using CR. This study also provides useful information on the ability to estimate true incidence by making use of CR.

MATERIALS AND METHODS

The materials are the data on cancer incidence in Aichi Prefecture, Japan, from 1976 to 1993. These materials have been derived from annual reports of cancer incidence in Aichi Prefecture¹⁰. Numbers for incidence, deaths, and DCN cases are obtained for total cancer and cancer at selected sites as available in the reports: that is, esophagus, stomach, colon, rectum, liver, biliary tract, pancreas, lung, and leukemia in males, stomach, colon, rectum, liver, biliary tract, pancreas, lung, breast, uterus, ovary, and leukemia in females. The International Classification of Disease, 9th revision (ICD-9)¹¹ was used to classify these sites.

In Aichi Cancer Registry, there is a two-year time lag between the year of diagnosis and determination of DCN cases of cancer (ICD-9: 140-208) of the year. DCN cases were not traced back. If DCN cases are determined before the arrival of notification, these cases are considered DCN cases when cancer incidence reports are provided. Incidence and deaths were available by gender, age-group and cancer site, while the number of DCN cases was available by gender and cancer site. The population of Aichi Prefecture was defined by gender and age group according to annual vital statistic reports for Aichi Prefecture¹². The study period was divided into six 3-year

periods to expose the trend: 1976-1978, 1979-1981, 1982-1984, 1985-1987, 1988-1990, and 1991-1993.

The proportion of DCN cases and I/D ratio were calculated for each period by gender and cancer site using the data mentioned above. Then the degree of completeness of registration was calculated for gender and cancer site. Since the proportion of DCN cases during the study period in Aichi Prefecture was above 10 percent on the whole, a modified formula proposed by the Osaka Cancer Registry¹³, rather than that proposed by the International Association of Cancer Registries (IACR)² was applied in this study: We defined a, b, c, d as follows; a: registered cases who are dead, b: registered cases who are alive, c: unregistered cases who are dead, d: unregistered cases who are alive (undetected cases still alive). CR can be estimated as [final registrations/(final registrations +d)] or [(a+b+c)/(a+b+c+d)]. Here, proportion of DCN (PDCN) cases is defined as [c/(a+b+c)]. In using DCN cases to estimate completeness, we assumed that the proportion of unregistered cancer cancers which die [c/(c+d)] is the same as the proportion of registered cases which die [a/(a+b)], or d=bc/a. Then this formula can be expressed as: (a+b+c) / (a+b+c+d) = (a+b+c) / (a+b+c+bc/a)=1/[1+(bc/a)/(a+b+c)]= 1/[(1-PDCN) + PDCN/(a/a+b)]= (1-PDCN I/D)/(1-PDCN). Accordingly, the formula used in this study is as follows: CR=(1-PDCN I/D)/(1-PDCN).

Since age-specific values for CR were not available, we assumed that CR was uniform for all age-groups. Thus, the number of true incident cases was estimated by dividing observed incident cases by CR. Age-specific incidence rates were calculated for the study periods by gender and cancer site, and standardized using the world standard population as a standard. The true incidence rates (estimated incidence rate: EIR) by gender and site were estimated by dividing the observed age-standardized incidence rate (observed incidence rate: OIR) by CR.

RESULTS

Table 1 shows the time trends in the proportion of DCN, I/D ratio, and CR of the total number of cancer cases and of cancers at selected sites. CR for all cancer sites was 62-78 percent in males and 54-72 percent in females. In males, it was high for cancer of the esophagus, biliary tract, pancreas, and lung, and low for cancer of the stomach, colon, and rectum. In females, it was high for cancer of the biliary tract, pancreas, and lung, and low for cancer of the colon, breast and uterus. As a whole, it was higher in cancers with low I/D ratios than in those with high I/D ratios.

Table 2 shows the difference between the numbers of observed annual incident cases and true annual incident cases estimated during the study periods. Annually, an estimated 2,500 male cases and 3,000 female cases were unreported. They were unregistered cases which did not die. The estimated

Table 1. Time trends in the proportion of cases first notified via death certificate (DCN), ratio of incident cases to deaths (I/D ratio), and the degree of completeness of registration (CR) of the total number of cancer cases and of cancers at selected sites in Aichi Prefecture, Japan.

Sites	(ICD-9)	DCN (%)						I/D ratio						CR					
		year						year						year					
		76-78	79-81	82-84	85-87	88-90	91-93	76-78	79-81	82-84	85-87	88-90	91-93	76-78	79-81	82-84	85-87	88-90	91-93
[Male]																			
all sites	(140-208, 233.0)	65.3	56.3	51.3	40.9	32.9	29.7	1.20	1.27	1.26	1.39	1.50	1.52	0.62	0.65	0.72	0.73	0.76	0.78
esophagus	(150)	63.6	50.1	46.3	38.8	33.3	29.4	1.15	1.15	1.21	1.21	1.23	1.29	0.75	0.85	0.82	0.87	0.88	0.88
stomach	(151)	64.4	55.4	50.6	38.8	30.2	25.3	1.19	1.28	1.26	1.45	1.58	1.60	0.66	0.65	0.73	0.72	0.75	0.80
colon	(153)	59.2	46.8	42.3	33.3	23.8	18.8	1.34	1.46	1.53	1.76	1.99	2.14	0.51	0.59	0.61	0.62	0.69	0.74
rectum	(154)	55.1	43.7	37.7	28.6	20.8	15.4	1.32	1.50	1.53	1.84	2.09	2.26	0.61	0.61	0.68	0.67	0.71	0.77
liver	(155)	79.9	73.8	62.9	52.3	42.9	43.3	1.10	1.09	1.13	1.20	1.26	1.21	0.60	0.74	0.77	0.78	0.81	0.84
biliary tract	(156)	83.9	73.4	59.7	50.9	45.1	42.2	1.02	1.10	1.11	1.19	1.20	1.17	0.91	0.71	0.83	0.80	0.83	0.87
pancreas	(157)	77.9	68.7	63.7	52.1	49.9	47.2	1.08	1.06	1.07	1.12	1.08	1.08	0.73	0.86	0.88	0.86	0.92	0.93
lung	(162)	68.7	59.0	55.6	47.5	41.1	41.3	1.10	1.16	1.12	1.16	1.19	1.15	0.79	0.76	0.85	0.85	0.87	0.90
leukemia	(204-208)	73.4	63.3	52.2	47.3	40.6	33.8	1.11	1.16	1.22	1.15	1.17	1.31	0.69	0.73	0.76	0.86	0.88	0.84
[Female]																			
all sites	(140-208, 233.0, 233.1)	58.3	51.0	45.2	35.7	28.8	26.5	1.33	1.43	1.45	1.63	1.78	1.78	0.54	0.56	0.63	0.65	0.68	0.72
stomach	(151)	64.8	59.7	52.9	41.5	34.9	30.6	1.18	1.22	1.24	1.37	1.48	1.49	0.66	0.67	0.73	0.74	0.74	0.78
colon	(153)	67.0	50.7	47.1	36.3	26.4	21.8	1.27	1.50	1.48	1.69	1.91	2.02	0.46	0.49	0.57	0.61	0.67	0.72
rectum	(154)	56.1	53.6	41.8	30.0	20.5	17.6	1.34	1.39	1.52	1.90	2.00	2.01	0.57	0.55	0.63	0.61	0.74	0.79
liver	(155)	85.5	78.9	70.2	60.3	50.7	48.1	1.02	1.04	1.07	1.12	1.28	1.25	0.89	0.84	0.84	0.81	0.71	0.77
biliary tract	(156)	87.1	75.2	63.3	53.5	51.4	49.7	1.01	1.12	1.11	1.17	1.17	1.11	0.93	0.64	0.81	0.81	0.82	0.90
pancreas	(157)	81.4	73.3	63.1	58.2	50.9	52.6	1.05	1.07	1.11	1.07	1.13	1.06	0.78	0.80	0.82	0.91	0.87	0.94
lung	(162)	70.3	62.7	58.8	50.6	42.5	43.9	1.11	1.14	1.13	1.21	1.23	1.14	0.75	0.77	0.81	0.79	0.83	0.89
breast	(174, 233.0)	29.4	22.2	19.8	12.9	9.9	8.3	2.28	2.66	2.67	3.48	3.63	3.97	0.47	0.53	0.59	0.63	0.71	0.73
uterus	(179-182, 233.1)	34.5	27.1	22.7	16.1	12.6	11.8	2.02	2.29	2.42	2.76	3.24	3.15	0.47	0.52	0.58	0.66	0.68	0.71
ovary	(183)	61.4	61.8	47.6	38.4	31.5	28.5	1.19	1.27	1.34	1.39	1.75	1.48	0.70	0.56	0.69	0.76	0.65	0.81
leukemia	(204-208)	71.9	63.9	56.5	54.7	36.4	31.6	1.09	1.12	1.14	1.08	1.35	1.27	0.78	0.79	0.82	0.90	0.80	0.87

number of cases missed depended not only on the I/D ratio or CR, but also on the number of cases.

Table 3 shows the time trends in the OIR (per 100,000 person-years) and EIR (per 100,000 person-years), estimated by CR of total number of cancer cases and cancer at selected sites. The EIR for all sites was estimated as 252-280 in males and 213-207 in females compared with an OIR reported as 157.0-218.6 in males and 115.3-149.2 in females. The OIR was closer to the EIR for cancers with low I/D ratios than to those with high I/D ratios.

DISCUSSION

The purpose of this study was to estimate the true incidence of the total number of cancer cases and of cancers at selected sites in the population of Aichi Prefecture, Japan, using CR. CR is the proportion of observed incident cases by the sum of registered cases and DCN cases among the true number of incident cases in the population. Theoretically, the true number of cases in the population consists of cases notified and regis-

tered, DCN cases not notified during the lifetime of a patient, and unregistered cases those assumed not to result in death². In reality, we are unable to know the number and the proportion of the unregistered cases who do not die. If it is relatively easy in the population to reduce the proportion of DCN cases to a sufficiently low level, the incidence by the sum of registered cases and DCN cases approaches to the true incidence level. But if it is relatively difficult, other methods of estimation of true incidence level are needed.

In this study, the modified formula proposed by the Osaka Cancer Registry¹³⁾ rather than that proposed by IACR² was used. The formula proposed by IACR is approximates to the former formula when the proportion of DCN cases is relatively small, smaller than 10 percent, for instance. We suggest, therefore, that the formula used in this study is more appropriate for Aichi Prefecture where the proportion of DCN cases has exceeded 10 percent as a whole. On the other hand, the proportion of DCN cases in Aichi Prefecture has changed remarkably since 1976. It is not known to what extent the estimated actual incidence rates may have been distorted by such a large varia-

Table 2. Time trends in the average annual number of observed incident cases and true incident cases estimated by the degree of completeness of registration of the total number of cancer cases and of cancers at selected sites in Aichi Prefecture, Japan.

		number of observed incident cases (OIN)						estimated number of true incident cases (EIN)						estimated number of cases missed (EIN-OIN)					
		year						year						year					
Sites	(ICD-9)	76-78	79-81	82-84	85-87	88-90	91-93	76-78	79-81	82-84	85-87	88-90	91-93	76-78	79-81	82-84	85-87	88-90	91-93
[Male]																			
all sites	(140-208, 233.0)	4,209	5,064	5,729	7,058	8,525	9,526	6,750	7,760	7,920	9,680	11,260	12,200	2,540	2,690	2,190	2,620	2,740	2,670
esophagus	(150)	124	142	150	193	221	255	170	170	180	220	250	290	40	30	30	30	30	30
stomach	(151)	1,614	1,724	1,718	1,993	2,203	2,277	2,450	2,640	2,360	2,790	2,940	2,850	840	910	640	790	740	580
colon	(153)	193	275	341	488	710	934	380	460	560	780	1,030	1,270	190	190	210	300	320	330
rectum	(154)	229	281	321	402	522	592	380	460	470	600	730	770	150	180	150	200	210	180
liver	(155)	303	407	556	730	884	981	500	550	720	940	1,100	1,170	200	140	160	210	210	190
biliary tract	(156)	100	140	170	221	249	270	110	200	200	280	300	310	10	60	30	60	50	40
pancreas	(157)	165	204	249	292	345	393	230	240	280	340	380	420	60	30	30	50	30	30
lung	(162)	578	765	943	1,172	1,416	1,583	730	1,000	1,110	1,380	1,630	1,770	160	240	170	200	220	180
leukemia	(204-208)	130	137	151	162	158	178	190	190	200	190	180	210	60	50	50	30	20	30
[Female]																			
all sites	(140-208, 233.0, 233.1)	3,725	4,420	4,838	5,925	7,033	7,699	6,890	7,960	7,690	9,070	10,290	10,700	3,170	3,540	2,850	3,150	3,260	3,000
stomach	(151)	1,114	1,159	1,114	1,189	1,286	1,309	1,690	1,720	1,530	1,610	1,730	1,670	570	560	410	420	440	360
colon	(153)	197	277	334	475	670	847	430	570	580	780	1,000	1,180	230	290	250	310	330	340
rectum	(154)	163	206	221	291	331	381	290	370	350	480	450	490	120	170	130	180	120	100
liver	(155)	163	169	192	255	299	339	180	200	230	310	420	440	20	30	40	60	120	100
biliary tract	(156)	163	207	271	315	352	387	170	320	330	390	430	430	10	120	60	70	70	50
pancreas	(157)	97	150	183	216	263	281	120	190	220	240	300	300	30	40	40	20	40	20
lung	(162)	210	278	351	421	554	591	280	360	430	540	670	660	70	80	80	110	110	70
breast	(174, 233.0)	382	533	635	907	1,136	1,315	820	1,010	1,080	1,430	1,600	1,800	440	480	450	530	460	490
uterus	(179-182, 233.1)	536	575	563	668	691	705	1,150	1,110	960	1,010	1,020	990	620	530	400	340	330	280
ovary	(183)	98	138	159	189	255	262	140	250	230	250	390	320	40	110	70	60	140	60
leukemia	(204-208)	83	98	103	113	134	132	110	120	130	130	170	150	20	30	20	10	30	20

tion in the proportion of DCN cases over the study period, for it is impossible to know the exact number or the proportion of these missed cases who are unregistered and do not die.

Data on DCN cases were not available by age-group, which was one methodological issue in this study. Since this information was unavailable, we assumed that the proportion of DCN was uniform for all age-groups. But in fact, it may be that the proportion of DCN cases is larger in older age groups than in younger age groups, and therefore, in cancers with a large proportion of older patients, the crude proportion of DCN cases may be larger than would be an age-adjusted one. In this case, the crude I/D ratio may be smaller than would be an age-adjusted ratio. CR is affected by both the proportion of DCN cases and the I/D ratio, both denominator and numerator, in both positive and negative directions. Thus the interpretation of results is not a simple matter.

In spite of several limitation mentioned above, CR will be a useful tool to estimate the true cancer incidence in a population-based cancer registry. These values are of great importance in forming cancer control strategies, by which it is possible to estimate the burden of cancer, and to evaluate the needs

and demands of the health services in each population.

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Table 3. Time trends in the age-standardized* observed incidence rates (OIR) and true incidence rates estimated by the degree of completeness of registration (EIR) of the total number cancer cases and of cancers at selected sites in Aichi Prefecture, Japan.

Sites	(ICD-9)	OIR (per 100,000 person-years)						EIR (per 100,000 person-years)					
		year						year					
		76-78	79-81	82-84	85-87	88-90	91-93	76-78	79-81	82-84	85-87	88-90	91-93
[Male]													
all sites	(140-208, 233.0)	157.0	172.6	175.4	195.0	213.0	218.6	252	264	243	267	282	280
esophagus	(150)	4.8	5.0	4.7	5.3	5.5	5.7	6	6	6	6	6	7
stomach	(151)	59.8	58.3	52.2	54.5	54.4	51.9	91	89	72	76	73	65
colon	(153)	7.1	9.2	10.3	13.3	17.5	21.3	14	16	17	21	25	29
rectum	(154)	8.1	9.6	9.7	11.0	12.9	13.4	13	16	14	17	18	17
liver	(155)	11.3	13.7	16.8	19.8	21.8	22.3	19	18	22	25	27	27
biliary tract	(156)	3.8	4.9	5.3	6.3	6.2	6.2	4	7	6	8	7	7
pancreas	(157)	6.2	6.9	7.7	8.1	8.6	8.9	8	8	9	9	9	10
lung	(162)	22.1	26.6	29.2	32.6	35.3	36.1	28	35	34	38	41	40
leukemia	(204-208)	4.6	4.5	4.7	4.9	4.4	4.8	7	6	6	6	5	6
[Female]													
all sites	(140-208, 233.0, 233.1)	115.3	124.4	123.1	136.0	148.4	149.2	213	224	196	208	217	207
stomach	(151)	34.1	32.1	27.7	26.4	25.9	24.0	52	48	38	36	35	31
colon	(153)	6.0	7.8	8.4	10.5	13.7	15.5	13	16	15	17	20	22
rectum	(154)	5.1	5.7	5.5	6.6	6.9	7.2	9	10	9	11	9	9
liver	(155)	5.0	4.8	4.8	5.7	6.1	6.2	6	6	6	7	8	8
biliary tract	(156)	5.0	5.7	6.6	6.6	6.7	6.3	5	9	8	8	8	7
pancreas	(157)	3.0	4.2	4.5	4.7	4.9	4.8	4	5	6	5	6	5
lung	(162)	6.5	7.7	8.6	9.2	10.7	10.4	9	10	11	12	13	12
breast	(174, 233.0)	11.8	15.1	16.6	22.0	25.7	28.0	25	29	28	35	36	38
uterus	(179-182, 233.1)	16.7	16.4	14.4	15.7	15.4	15.0	36	32	25	24	23	21
ovary	(183)	3.1	4.0	4.2	4.6	5.8	5.6	4	7	6	6	9	7
leukemia	(204-208)	2.8	3.1	3.0	3.1	3.7	3.4	4	4	4	3	5	4

*by the world population

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