Research

Lack of active follow-up of cancer patients in Chennai, India: implications for population-based survival estimates

Rajaraman Swaminathan,[a] Ranganathan Rama,[a] & Viswanathan Shanta[a]

Objective To measure the bias in absolute cancer survival estimates in the absence of active follow-up of cancer patients in developing countries.

Methods Included in the study were all incident cases of the 10 most common cancers and corresponding subtypes plus all tobacco-related cancers not ranked among the top 10 that were registered in the population-based cancer registry in Chennai, India, during 1990–1999 and followed through 2001. Registered incident cases were first matched with those in the all-cause mortality database from the vital statistics division of the Corporation of Chennai. Unmatched incident cancer cases were then actively followed up to determine their survival status. Absolute survival was estimated by using an actuarial method and applying different assumptions regarding the survival status (alive/dead) of cases under passive and active follow-up.

Findings Before active follow-up, matches between cases ranged from 20% to 66%, depending on the site of the primary tumour. Active follow-up of unmatched incident cases revealed that 15% to 43% had died by the end of the follow-up period, while the survival status of 4% to 38% remained unknown. Before active follow-up of cancer patients, 5-year absolute survival was estimated to be between 22% and 47% higher, than when conventional actuarial assumption methods were applied to cases that were lost to follow-up. The smallest survival estimates were obtained when cases lost to follow-up were excluded from the analysis.

Conclusion Under the conditions that prevail in India and other developing countries, active follow-up of cancer patients yields the most reliable estimates of cancer survival rates. Passive case follow-up alone or applying standard methods to estimate survival is likely to result in an upward bias.

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Une traduction en français de ce résumé figure à la fin de l'article. *Al final del artículo se facilita una traducción al español.* الترجمة العربية لهذه الخلاصة في نهاية النص الكامل لهذه المقالة.

Introduction

In recent decades, incident cancer cases have been systematically and continuously registered all over the world using both active and passive methods. Passive registration methods, which may or may not be facilitated by the law, are those in which incident cancer cases are notified and the data are involuntarily received by the registry from the respective sources. Active cancer registration methods consist of collecting data from other sources voluntarily. Data from 53 registries in 25 developing countries were published in 2002 by the International Agency for Research on Cancer in Lyon, France.[1] Cancer was a notifiable disease in 49% of the 53 registries, while data on incident cancers were collected entirely by passive methods in 34%. In less than one-third of the registries practising passive registration, data linkages were based on unique identification numbers.[1]

In India, cancer is not a notifiable disease. Hence, cancer cases are primarily registered through active methods.[2–6] The population-based cancer registry (PBCR) in Chennai, known as the Madras Metropolitan Tumour Registry (MMTR), is based at the Cancer Institute (Women's India Association) and has been a part of the National Cancer Registry Program of the Indian Council of Medical Research, a government entity, since 1981.

Official cancer mortality data from the vital statistics division is generally integrated into the PBCR. However, in most developing countries, including India, death certificates are often inaccurate, so that all-cause mortality data should be used to supplement cancer mortality statistics.[7]

Having reliable information on survival from cancer has long been recognized as important for cancer control activities. Monitoring population-based survival rates is useful for patient care and health care planning. Such rates are free from case selection bias and reflect average cancer-related outcomes in a given region. Population-based cancer survival estimates have been increasingly available in developing countries since the early 1990s, but at least one-third of them are based exclusively on passive follow-up.[8] The present study aims to measure the bias resulting from absolute survival estimates in the absence of active case follow-up and when different assumptions are made regarding the survival status of cancer patients in developing countries.

[a] Division of Epidemiology and Cancer Registry, Cancer Institute (Women's India Association), 38 Sardar Patel Road, Chennai 600036, India.
Correspondence to Rajaraman Swaminathan (e-mail: iarcsurvival@yahoo.co.uk).
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Table 1. **Survival status of incident cancer cases registered in 1990–1999 and followed through 2001, PBCR, Chennai, India**

Tumour site/type	Cases included in survival analysis	Passive follow-up	Active follow-up		
		Matched deaths (%)	Additional deaths identified (%)	Cases alive at closing date (%)	Survival status unknown at closing date (%)
Lip	86	19.8	33.7	11.6	34.9
Tongue	988	37.6	32.5	5.5	24.4
Oral cavity	1662	31.8	31.5	10.2	26.5
Tonsil	250	42.8	42.8	6.4	8.0
Hypopharynx	1017	41.4	40.5	5.8	12.3
Oesophagus	2016	51.0	36.3	2.9	9.8
Stomach	2681	51.9	33.0	4.5	10.6
Pancreas	328	57.9	30.8	7.0	4.3
Larynx	722	40.2	23.0	19.6	17.2
Lung	1806	59.2	28.0	2.4	10.4
Breast	3067	28.5	20.0	28.2	23.3
Cervix	4438	25.5	16.7	19.8	38.0
Ovary	808	39.7	20.5	17.2	22.6
Urinary bladder	442	38.9	30.1	14.0	17.0
Hodgkin lymphoma	298	30.9	26.5	24.8	17.8
Non-Hodgkin lymphoma	868	44.1	25.2	15.0	15.7
Lymphoid leukaemia	433	45.5	29.1	11.3	14.1
Myeloid leukaemia	465	59.6	18.9	7.5	14.0
Leukaemia, type unspecified	85	65.9	15.3	5.9	12.9

PBCR, population-based cancer registry.

Methods

Included in the study were all incident cases of the 10 most common broadly-defined cancers and corresponding subtypes (for cancers of the oral cavity, lymphomas and leukaemias), plus tobacco-related cancers not ranked among the top 10 (such as pancreas and urinary bladder), that were registered in the MMTR in Chennai during 1990–1999 and followed through 31 December 2001.

Data on incident cancer cases in the MMTR were obtained by direct interview of patients by cancer registrars at selected source hospitals at the time of registration and/or by perusal of medical records at those hospitals using a validated, standardized questionnaire common to all registries in India. Interviewers were trained by senior investigators of the registry project at the base institution where the registry is physically located.[3] Data on cancer deaths through 1991 and on all-cause mortality since 1992 were extracted from death certificates maintained at the vital statistics division of the Corporation of Chennai.[3,7] Incident cancer cases in the MMTR were then matched with cases in the mortality database primarily using each individual's personal identity details. Cancer cases for which no matches were found in the mortality database were actively followed to determine their survival status. Medical records at source hospitals that imposed restrictions on active follow-up were examined once every 3 years or less in order to track patients' attendance at clinical follow-up visits. Postal or telephone enquiries among patients or their relatives and friends and other contacts were carried out by cured cancer patients from the locality, volunteer service organizations, and health workers. House visits, which make it possible to interrogate neighbourhood residents, are the most common active follow-up method pursued by patient registries in India to effectively determine the survival status of patients who have migrated (common in urban areas).

Different actuarial assumptions on the survival status of subjects were made during follow-up for the purpose of this study. Subjects were designated as belonging to the following categories: (A) when they were matched with mortality data obtained by routine registry data linkage with official mortality statistics without any active follow-up; (B) when they could not be matched through routine registry data linkage with official mortality statistics and their death was ascertained through active follow-up; (C) when they were lost to follow-up but known to be alive until a specific date, with unknown survival status at the close of follow-up; and (D) when they had completed follow-up and were known to be alive on the closing date.

The follow-up status was classified into four different case scenarios depending on the assumptions made, as follows:

Case 1: Passive follow-up only of cancer cases not matched with official mortality data but presumed to be alive at the close of follow-up. In this scenario, subjects in category A were treated as having died on their respective dates of death, while subjects B, C, and D were treated as having been alive on the last day of follow-up.

Case 2: Passive and active follow-up, with cases lost to follow-up presumed to be alive on the last day of follow-up. In this scenario, subjects A and B were treated as having died on their respective dates of demise, while subjects C and D were treated as having been alive on the last day of follow-up.

Table 2. **Incident cancer cases included in the survival analysis, among those registered in 1990–1999 and followed through 2001, PBCR, Chennai, India**

Tumour site/type	Number of cases included in survival analysis									
	Total	Passive follow-up only		Passive and active follow-up						
		Case 1[a]		Case 2[b]		Case 3[c]			Case 4[d]	
		Dead	Presumed alive at closing date	Dead	Presumed alive at closing date	Dead	Alive	Lost to follow-up	Dead	Alive
Lip	86	17	69	46	40	46	10	30	46	10
Tongue	988	371	617	693	295	693	54	241	693	54
Oral cavity	1662	528	1134	1052	610	1052	169	441	1052	169
Tonsil	250	107	143	214	36	214	16	20	214	16
Hypopharynx	1017	421	596	833	184	833	59	125	833	59
Oesophagus	2016	1028	988	1759	257	1759	59	198	1759	59
Stomach	2681	1392	1289	2277	404	2277	120	284	2277	120
Pancreas	328	190	138	291	37	291	23	14	291	23
Larynx	722	290	432	456	266	456	142	124	456	142
Lung	1806	1069	737	1574	232	1574	45	187	1574	45
Breast	3067	875	2192	1489	1578	1489	862	716	1489	862
Cervix	4438	1131	3307	1874	2564	1874	878	1686	1874	878
Ovary	808	321	487	487	321	487	138	183	487	138
Urinary bladder	442	172	270	305	137	305	62	75	305	62
Hodgkin lymphoma	298	92	206	171	127	171	74	53	171	74
Non-Hodgkin lymphoma	868	383	485	602	266	602	130	136	602	130
Lymphoid leukaemia	433	197	236	323	110	323	49	61	323	49
Myeloid leukaemia	465	277	188	365	100	365	35	65	365	35
Leukaemia, type unspecified	85	56	29	69	16	69	5	11	69	5

PBCR, population-based cancer registry.

[a] Case 1: Passive follow-up only, with cancer cases not matched with those in the official mortality database presumed to be alive on the closing date.

[b] Case 2: Passive and active follow-up, with cases lost to follow-up presumed to be alive on the closing date.

[c] Case 3: Passive and active follow-up, with cases lost to follow-up censored on the last date their survival status was known.

[d] Case 4: Passive and active follow-up, with cases lost to follow-up excluded from survival analysis.

Case 3: Passive and active follow-up, with cases lost to follow-up censored on the last date on which their survival status was known. Under this case scenario, subjects A and B were treated as having died on their respective dates of demise; subjects in category D were treated as having been alive on the last day of follow-up, and subjects in category C were treated as having been alive until a specific date and censored thereafter for the survival analysis, based on actuarial assumption.

Case 4: Passive and active follow-up, with cases lost to follow-up excluded from the survival analysis. This resembles Case 3, excepting that subjects in category C were excluded from the survival analysis.

Absolute survival probability, also known as crude survival, was estimated through an actuarial approach.[9] However, the assumptions made in this study differed from those normally made using the routine actuarial method.

Findings

Table 1 gives the survival status of incident cancer cases, for primary tumours of different types, in accordance with the follow-up method used. Deaths in the all-cause mortality database that were matched with cases in the incident cancer database without any active follow-up ranged between 20% (lip cancer) and 66% (leukaemias, type unspecified). Of those cancer cases having no match in the mortality database and actively followed, 15% (leukaemia, type unspecified) to 43% (cancer of the tonsil) had died, and 3% (oesophageal cancer) to 28% (female breast cancer) were alive by the end of the follow-up period. Survival status was unknown in 4% (pancreatic cancer) to 38% (cervical cancer) of the cases on the last day of follow-up. As shown in Table 2, a variable number of cases, depending on survival status, was used to estimate absolute survival under different actuarial assumptions at follow-up.

Table 3 shows the frequency (%) of losses to follow-up at varying time intervals from the time of diagnosis: < 1 year, 1–3 years, 3–5 years and > 5 years. This information can be obtained only through active follow-up. For most primary tumour sites, the highest proportion of losses to follow-up occurred within the first year from diagnosis, with figures ranging from 3% for lymphoid leukaemia to 15% for ovarian cancer cases. From about 1% of pancreatic cancer to 26% of lip cancer cases were lost to follow-up after 5 years from diagnosis. Very small proportions

were lost to follow-up between 1–3 years and 3–5 years from diagnosis.

Table 4 gives the 5-year absolute survival (%) estimated by actuarial methods under different assumptions on the survival status of subjects that were followed passively, actively, or both. The differences in 5-year absolute survival, in percentages, between cases 1 and 2 were smallest among cases of leukaemia (type unspecified) (15.1%), cervical cancer (16.5%), and myeloid leukaemia (18.9%), and highest among patients with cancers of the tonsil (41.3%), hypopharynx (39.2%), and lip (34.9%). In the absence of active follow-up (case 1), 5-year absolute survival was estimated to be higher by 22% (leukaemia, type unspecified) to 47% (hypopharyngeal cancer) than when cases were actively followed and were lost to follow-up at a known point in time (case 3). In relative terms, odds ratios (OR) reflecting survival differences were largest for oesophageal cancer (OR: 12.9) and smallest for leukaemia (type unspecified) (OR: 4.0). Cases 2 and 4 represent the two extremes of a survival spectrum, with the actuarial estimate assuming random withdrawal falling somewhere in between. The more losses to follow-up, the greater the uncertainty and potential for bias in the actuarial estimate. The absolute differences in 5-year survival between cases 2 and 4 were substantial for cancers of the tongue (13.8%) and ovary (18.4%).

Table 3. **Distribution of incident cancer cases lost to follow-up, among those registered in 1990–1999 and followed through 2001, PBCR, Chennai, India**

Tumour site/type	Losses to follow-up by years from diagnosis (%)			
	< 1	1–3	3–5	> 5
Lip	7.0	2.3	0.0	25.6
Tongue	13.1	2.6	1.2	7.5
Oral cavity	10.3	2.2	1.8	12.2
Tonsil	4.8	0.8	0.0	12.4
Hypopharynx	9.0	0.6	0.0	2.3
Oesophagus	6.7	0.9	0.4	1.8
Stomach	7.3	0.9	0.9	1.5
Pancreas	3.1	0.3	0.3	0.6
Larynx	6.7	0.8	0.3	9.4
Lung	8.0	0.7	0.3	1.4
Breast	12.4	2.9	2.0	6.0
Cervix	11.0	3.7	2.5	20.8
Ovary	14.7	4.6	1.4	1.9
Urinary bladder	10.9	1.6	0.2	4.3
Hodgkin lymphoma	6.4	1.7	1.0	8.7
Non-Hodgkin lymphoma	10.9	1.3	0.6	2.9
Lymphoid leukaemia	2.8	3.2	3.5	4.6
Myeloid leukaemia	8.6	1.3	0.4	3.7
Leukaemia, type unspecified	10.5	0.0	0.0	2.4

PBCR, population-based cancer registry.

Discussion

Survival estimates of unselected groups of cancer patients from population-based cancer registries can serve as an important index for evaluating cancer diagnosis and treatment and the effectiveness of overall cancer services in a given region.[8] Of the 53 registries from 25 developing countries that published data on cancer incidence and mortality in 2002, less than half have published data on cancer survival despite their long history of cancer registration.[1,8] In India, only six out of more than 20 registries have undertaken survival studies.[2,8]

Unlike mortality data collection, follow-up is not usually integrated with routine population-based cancer registration practices. In most developed countries, passive follow-up of cancer patients is carried out through the use of a personal identification number (PIN) matched with mortality databases. In making survival analyses, cancer cases are presumed to be alive when no information on death has been traced by a particular reference date. For losses to follow-up, non-informative or random censoring is anticipated (i.e. the losses to follow-up are assumed to be independent of the risk of death). However, in most developing countries, including India, unique citizen identifiers (such as PINs) do not exist; mortality registration systems, especially medical certification of deaths, are deficient, and the identity particulars of deceased individuals are often inaccurate. Thus, passive means of follow-up alone may not be sufficient to perform a meaningful survival analysis.

Ten registries from five developing countries contributed data on survival for the first time to the International Agency for Research on Cancer monograph on *Cancer survival in developing countries*,[8] and four of them (Qidong and Shanghai registries from China; Cuba; and Rizal from the Philippines) relied either entirely or predominantly on passive follow-up methods. All four registries from India (Bangalore, Barshi, Bombay and Madras) that contributed data to that monograph had employed active follow-up. In the forthcoming second volume of the same publication, many more registries submitted data on survival and several of them adhered to passive methods of follow-up. Thus, active methods are needed and the effect of passive registry follow-up on survival estimates should be ascertained. The authors have done this by using data from the Chennai registry in India and generalizing their conclusions to other developing countries.

The Chennai registry has collected data on all-cause mortality from the vital statistics division of the Corporation of Chennai since 1992. The general mortality-to-cancer incidence ratio was 45% in 1992–2001 and 23% before 1992, when only cancer mortality data were available.[7] However, this did not account for all the deaths that had occurred among the incident cancer cases in the Chennai cancer registry. The active follow-up of cancer cases that could not be matched with cases in the all-cause mortality database revealed additional deaths, ranging from 15% more deaths among patients with leukaemia (type unspecified) to 43% more deaths among patients with cancer of the tonsil. The main reasons deaths could not be unambiguously matched with cases in the cancer registry data-

base were: (i) incomplete identity information about the deceased in death certificates/records; (ii) migration of cases within the registry area before death, and (iii) inaccurate details given by persons reporting the death. These factors are difficult to overcome despite the full availability of cause-specific mortality data in the region under study.

If invalid actuarial assumptions are made, deaths are underreported and the impact on absolute survival is large. Studies from developed countries employing unique case identifiers to link data passively have acknowledged the need to correct for survival status (alive/dead) through active follow-up, as well as the potential impact of active follow-up on survival.[10,11]

In our study, losses to follow-up were most frequent within 1 year of diagnosis.[12–16] A different pattern has been observed in Thailand, with the highest losses occurring more than 5 years from diagnosis.[8] Losses to follow-up at varying times thus affect actuarial survival estimates under passive follow-up. The highest dropout rates within the first year of cancer diagnosis are often due to death, while the long-term losses to follow-up occur mainly among survivors. Many studies exclude cases that are lost to follow-up from survival analyses.[8,13,15] As shown by our case 4 scenario, such exclusions may result in a substantial bias whose magnitude depends on the number of losses to follow-up, with losses not occurring randomly or independently of the risk of death. Loss-adjusted survival methods have been proposed[17] and applied to survival studies, with many losses to follow-up considered non-random.[13,18] After adjusting for cases lost to follow-up in these studies, only minimal differences were noted, ranging from 1% to 5% based on the data obtained from the population-based cancer registry, indicating that the losses were practically random. However, the same could not be said of survival studies using hospital cancer registry data, with differences in the order of 15%.[13,17] These differences typically represent the advantages of using population-based cancer registry data rather than hospital series.

The study clearly shows that in a population-based cancer registry series, passive follow-up, as represented by our case 1 approach, is unidirectional and leads to potentially biased survival estimates. Our case 3 scenario – applying an actuarial approach after improving the follow-up data by using an active method – provides a closer estimate of true survival. Cases 2 and 4 yield the largest and smallest residual bias, respectively, when the follow-up data ascertained by the active method is incomplete. Using a loss-adjusted survival approach is meaningless if the missing data is associated with the risk of death and with prognostic factors. A more complete analysis would bring out whether true differences existed between the four case scenarios.

Table 4. **Five-year absolute survival under different assumptions regarding survival status among incident cancer cases registered in 1990–1999 and followed through 2001, PBCR, Chennai, India**

Tumour site/type	5-year absolute survival (%)			
	Passive follow-up	Active follow-up		
	Case 1[a]	Case 2[b]	Case 3[c]	Case 4[d]
Lip	79.5	44.6	40.7	39.5
Tongue	62.1	29.2	19.4	15.4
Oral cavity	68.5	37.1	30.5	26.4
Tonsil	58.5	17.2	13.7	10.8
Hypopharynx	59.2	20.0	12.5	9.6
Oesophagus	48.9	12.9	6.9	5.0
Stomach	47.9	15.0	8.6	5.6
Pancreas	41.8	10.9	7.9	6.5
Larynx	59.0	35.1	30.7	28.4
Lung	40.8	13.2	6.5	4.2
Breast	71.6	51.5	43.7	39.6
Cervix	75.5	59.0	54.0	49.4
Ovary	60.1	39.5	27.4	21.1
Urinary bladder	61.3	31.0	23.2	20.0
Hodgkin lymphoma	69.1	42.6	39.4	35.9
Non-Hodgkin lymphoma	55.6	29.7	21.6	16.8
Lymphoid leukaemia	54.3	26.5	23.8	15.5
Myeloid leukaemia	40.4	21.5	14.7	10.9
Leukaemia, type unspecified	32.9	17.8	10.9	6.2

PBCR, population-based cancer registry.
[a] Case 1: Passive follow-up only, with cancer cases not matched with those in the official mortality database presumed to be alive on the closing date.
[b] Case 2: Passive and active follow-up, with cases lost to follow-up presumed to be alive on the closing date.
[c] Case 3: Passive and active follow-up, with cases lost to follow-up censored on the last date their survival status was known.
[d] Case 4: Passive and active follow-up, with cases lost to follow-up excluded from survival analysis.

Conclusion

Under the conditions that prevail in India and other developing countries, with incomplete mortality registration, no unique case identifiers for linking data and poor health information systems, active follow-up of cancer patients yields the most reliable estimates of cancer survival rates. Passive follow-up alone and standard methods of estimating survival are likely to result in an upward bias. ■

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Competing interests: None declared.

Résumé

Manque de suivi actif des patients cancéreux à Chennei, en Inde: implications pour les estimations du taux de survie en population

Objectif Mesurer le biais affectant les estimations du taux de survie absolue au cancer en l'absence de suivi actif des patients cancéreux dans les pays en développement.

Méthodes Ont été inclus dans l'étude tous les cas incidents des 10 cancers les plus courants et des sous-types correspondants, plus tous les cancers liés au tabac non classés parmi les 10 premièrs recensés dans le registre des cancers de la population de Chennei, en Inde, au cours de la période 1990-1999, et suivis jusqu'en 2001. Les cas incidents enregistrés ont d'abord été appariés avec ceux figurant dans la base de données de mortalité toutes causes confondues de la division statistiques vitales de la Corporation de Chennei. Les cas de cancer incidents non appariés ont ensuite fait l'objet d'un suivi actif pour déterminer leur statut de survie. Le taux de survie absolue a été estimé en utilisant une méthode actuarielle et en appliquant différentes hypothèses concernant le statut de survie (vivant/mort) des cas, dans les situations de suivi passif et actif.

Résultats Avant le suivi actif, l'appariement obtenu allait de 20 à 66 %, selon le site de la tumeur primaire. Un suivi actif des cas incidents non appariés a révélé que 15 à 43 % d'entre eux étaient décédés à la fin de la période de suivi et que le statut de survie de 4 à 38 % de ces cas restait inconnu. Avant le suivi actif des patients cancéreux, on estimait que le taux de survie absolue à 5 ans se situait entre 22 et 47 %, soit plus qu'après l'application aux cas perdus pour le suivi de méthodes actuarielles hypothétiques classiques. Les estimations les plus faibles des taux de survie ont été obtenues en excluant les cas perdus pour le suivi de l'analyse.

Conclusion Dans les conditions qui prévalent en Inde et dans d'autres pays en développement, le suivi actif des patients cancéreux fournit les estimations les plus fiables des taux de survie au cancer. Le suivi passif seul ou l'application de méthodes classiques pour estimer la survie sont susceptibles d'entraîner un biais haussier.

Resumen

Falta de seguimiento activo de los pacientes con cáncer en Chennai, India: implicaciones para las estimaciones de supervivencia basadas en la población

Objetivo Medir el sesgo de las estimaciones absolutas de la supervivencia de los enfermos de cáncer en ausencia de medidas de seguimiento activo de esos pacientes en los países en desarrollo.

Métodos El estudio abarcó todos los casos nuevos de los 10 cánceres más comunes y sus distintos subtipos, más todos los cánceres relacionados con el tabaco y no clasificados entre los 10 principales, que habían sido incluidos en el registro de cáncer basado en la población en Chennai, India, durante 1990–1999, y sometidos a seguimiento durante 2001. Los casos nuevos registrados se aparearon con los de la base de datos de mortalidad por todas las causas de la división de estadísticas vitales de la corporación municipal de Chennai, y los casos nuevos no apareados fueron sometidos luego a seguimiento activo para determinar su grado de supervivencia. La supervivencia absoluta se estimó mediante un método actuarial, aplicando diferentes supuestos respecto al estado de supervivencia (vivo/muerto) de los casos sometidos a seguimiento pasivo y activo.

Resultados Antes del seguimiento activo, el apareamiento entre casos osciló entre el 20% y el 66%, según la localización del tumor primario. El seguimiento activo de los casos nuevos no apareados reveló que entre un 15% y un 43% habían fallecido al final del periodo de seguimiento, y no se conocía el estado de supervivencia de un 4%-38% de los casos. Antes del seguimiento activo de los enfermos de cáncer, su supervivencia absoluta a los 5 años era según las estimaciones un 22%-47% superior a la determinada al aplicar los supuestos actuariales tradicionales a los casos perdidos para el seguimiento. Las estimaciones de supervivencia más bajas fueron las obtenidas al excluir de los análisis los casos perdidos para el seguimiento.

Conclusión En las condiciones reinantes en la India y en otros países en desarrollo, el seguimiento activo de los enfermos de cáncer es el método más fiable para estimar las tasas de supervivencia del cáncer. El simple seguimiento pasivo de los casos o la aplicación de los métodos habituales de estimación de la supervivencia tienden a ocasionar un sesgo por exceso.

ملخص

فقد المتابعة الفعَّالة لمرضى السرطان في شنّاي، الهند: تأثير تقديرات البُقيا السكانية

الهدف: قياس التحيُّز في تقديرات البُقْيَا (البقاء على قيد الحياة) المطلقة لدى مرضى السرطان عند فقد المتابعة الفعَّالة لمرضاه في البلدان النامية.

الطريقة: شملت الدراسة جميع الحالات التي وقعت من أنماط السرطان العشرة الأكثر شيوعاً مع الأنماط الفرعية المتعلقة بها، والسرطانات المرتبطة بالتبغ والتي لم تصنَّف ضمن تلك الأنماط العشرة، وسُجِّلت في سجل سكاني للسرطان في شنّاي، الهند، وذلك في خلال الفترة 1990 – 1999، وتمت متابعتها خلال عام 2001. وأجرى الباحثون مقارنة بين الحالات المسجلة أولاً وبين الحالات الموجودة في قاعدة معطيات للوفيات الناجمة عن جميع الأسباب في قسم الإحصاءات المدنية الحيوية في مؤسسة شنّاي. ثم أجري الباحثون بعد ذلك متابعة فعّالة للتعرف على أوضاع الحالات التي لم تكن متوافقة مع قاعدة المعطيات، من حيث بقائها على قيد الحياة. وقدّر الباحثون المعدل المطلق للبقيا باستخدامهم طريقة حسابية (إكتوارية) وافتراضات مختلفة تتعلق بأوضاع البقيا (أحياء/أموات) للحالات التي طبق عليها المتابعة الفعَّالة واللافاعلة.

الموجودات: قبل القيام بالمتابعة الفعَّالة، تراوح التوافق بين الحالات بين 20% و66% ويعتمد ذلك على موقع الورم البدئي. فيما دلت المتابعة الفعَّالة لوقوع الحالات غير المتوافقة أن ما يتراوح بين 15% و43% قد ماتوا قبل حلول نهاية فترة المتابعة فيما بقيت حالة البقيا لدى 4% إلى 38% منهم غير معروفة.

وقبل المتابعة الفعَّالة لمرضى السرطان، قدر الباحثون أن معدل البُقْيَا المطلق لمدة 5 سنوات يزيد بمقدار يتراوح بين 22% و47% على ما سيكون عليه عند تطبيق الطرق التقليدية الحسابية الإكتوارية على الحالات التي فقدت من المتابعة. وقد حصل الباحثون على أقل قدر من تقديرات البُقْيَا عند استبعاد الحالات التي فقدت من المتابعة أثناء التحليل.

الاستنتاج: في ظل الظروف السائدة في الهند وفي البلدان النامية الأخرى، أدت المتابعة الفعَّالة إلى الحصول على تقديرات لمعدل وفيات السرطان هي الأكثر موثوقية. أما المتابعة اللافاعلة للحالات أو تطبيق الطرق المعيارية لتقدير البُقْيَا فتؤدي في الغالب إلى تحيُّز يميل للزيادة.

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