Capture-recapture method to estimate lower extremity amputation rates in Rio de Janeiro, Brazil

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ABSTRACT

Objective. *To estimate rates of lower extremity amputations (LEAs) in persons with peripheral vascular disease, diabetes mellitus, trauma, neoplasm, osteomyelitis, or emphysematous gangrene.*

Methods. *Regional amputee registries were used to estimate the rate of lower extremity amputations with the capture-recapture (CR) technique. Data were extracted from three amputee registries in Rio de Janeiro: source 1, with 1 191 cases from 23 hospitals; source 2, with 157 cases from a limb-fitting center; and source 3, with 34 cases from a rehabilitation center.*

Amputee death certificates from source 1 identified 257 deaths from 1992 to 1994. Three CR models were evaluated using sources 2 and 3. In order to avoid an overestimation of the rate of LEAs, two models were applied for the data analysis: in one case, deceased patients listed in source 1 were excluded from the model, and in the other case, deceased patients were included as well.

Results. *Excluding the 257 deaths, the estimated number of amputations in the municipality of Rio de Janeiro from 1992 to 1994 was 3 954, for a mean annual incidence rate of 13.9 per 100 000 inhabitants. Among persons with diabetes, the annual incidence rate of lower extremity amputations was substantially higher (180.6 per 100 000 persons per year), representing 13 times the risk of individuals without diabetes. The yearly rate of LEAs according to the routine surveillance system was estimated at 5.4 and 96.9 per 100 000 in the general population and in diabetics, respectively. If data from the three registries are added, 1 382 patients with LEAs were identified, with the reasons for the amputations distributed as follows: peripheral vascular disease = 804 (58.1%); diabetes mellitus = 379 (27.4%); trauma = 103 (7.4%); osteomyelitis = 44 (3.1%); gangrene = 36 (2.6%), and neoplasm = 16 (1.1%).*

Conclusions. *These findings show a high incidence of LEAs in Brazil, when compared to countries such as Spain, that is attributable mainly to peripheral vascular disease and diabetes mellitus.*

Key words Lower extremity amputation, diabetes mellitus, peripheral vascular disease, neoplasm, osteomyelitis, emphysematous gangrene, trauma, capture-recapture

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Lower extremity amputation (LEA) is a major health problem in the general population and is associated with significant morbidity, mortality, and disability. An amputation is not merely the loss of a limb; it can also mean job-

lessness, disability, high insurance payments, and a poor quality of life. In the United States of America and in Sweden, 50% and 32%, respectively, of all non-traumatic amputations occur in people who have diabetes (1).

In 1987, 56 000 non-traumatic LEAs were performed among people with diabetes in the United States (2). Among diabetics, the relative risk of LEA is approximately 40 times higher than in nondiabetics (3).

In the Oklahoma Indian Diabetes Study, the annual incidence of first LEAs among diabetic patients was 18.0 per 1 000 (4).

A review of the literature beginning in the 1970s (Table 1) indicates that current information on the frequency of LEAs is limited everywhere (4–20). Estimates of LEA annual incidence range from 68 to nearly 1 712 per 100 000 in an American Indian population and in Leicester, England, respectively (7, 11). In the nondiabetic population, the incidence ranges from 2 to 220 per 100 000 in Newcastle, England, and among Pima Indians, respectively (5, 12).

The prevalence of peripheral vascular disease (PVD) is higher in diabetic than nondiabetic subjects in population-based and clinic-based studies, ranging from 5.1% to 38.9%, respectively (21). PVD is among the most important reasons for LEA in individuals with and without diabetes (22).

Gangrene and osteomyelitis are two significant indications for amputations in persons with diabetes, as seen in the United Kingdom (23) and in Spain (24). The annual general incidence rate of LEA in the Netherlands has hovered between 18 and 20 per 100 000 over the last 12 years, and oncologic and traumatic reasons together have accounted for 3% of this incidence, which is among the lowest in Western Europe (25).

Examining the differences in LEA rates by groups of people within communities, especially by applying the same methodology, helps to identify and target high-risk groups (26).

The methodology described here makes use of capture-recapture (CR) modeling to estimate the number of LEAs in the municipality of Rio de Janeiro during the period from 1992 to 1994, according to a breakdown into six different etiologic categories: PVD, diabetes mellitus, osteomyelitis, trauma, emphysematous gangrene, and tumor.

For most diseases, ascertainment rates in traditional passive surveillance systems are acknowledged to be low and inconsistent. Registries (i.e., active surveillance systems), by contrast, have much higher degrees of ascertainment. Approaches for adjusting estimates to reflect ascertainment level (or census undercount) are collectively referred to as capture-recapture methods (27).

It is our belief that CR technology provides a formal means for estimating the degree of undercount of a health problem within a population and for cost-effective and timely universal monitoring of all serious disease. With these powerful tools, considerably more accurate incidence and prevalence rates will be available for comparisons between populations. CR technique allows the number of new cases of diseases in a defined population to be accurately estimated using two or more sources (27).

Table 2 shows a comparison between the traditional method and the ascertainment-corrected or CR method for determining disease rates (28–39). The examples presented illustrate how easily ascertainment correction methods can be applied to complement existing surveillance systems. This approach was useful in estimating the underreporting of pulmonary tuberculosis in Spain (28), lupus erythematosus in Denmark (35), Addison's disease in Italy (37), and AIDS cases in France (39).

Another recent study performed by the Eurodiab Ace Study Group (40) examined the onset of type 1 diabetes in

TABLE 1. Annual incidence (per 100 000) of lower extremity amputations (LEAs) as determined by a review of the literature and data from selected countries. 1972–1994

	Incidence	
Population, reference, years	General population	Diabetic population
Oklahoma Indians, USA (4) 1972–80	—	1 800
Pima Indians, USA (5) 1972–84	220	1 370
Wisconsin, USA (6) 1980–86	—	550
Indian Health Service, USA (7) 1982–87	—	1 721 (Tucson)
		1 364 (Phoenix)
		651 (Oklahoma)
		535 (Navajo)
Chippewa Indians, USA (8) 1986–88	—	1 600
Cherokee Indians, USA (9) 1982–89	—	1 210
Ontario, Canada/USA (10) 1987–88	—	444
Leicester, England (11) 1980–85	17 WM[a]	
	13 WW[a] 5 AM[a]	
	2 AW[a]	175 WM[a] 108 WWa
		68 AM[a]
		0 AW[a]
Newcastle upon Tyne, England (12) 1989–91	—	570
Eastern Finland (13) 1978–84	33.9 men	349 men
	17.3 women	239 women
Southern Finland (14) 1984–85	32.5 (1984)	
	28.1 (1985)	
Motala, Sweden (15) 1980–82	46	
Tayside, Scotland (16) 1980–82	—	101
Australian states (17) 1981–85	23.6 (1984)	
Denmark (18) 1978–89	25.767	
Spain (19) 1989–93	3.47	69.74
Rio de Janeiro, Brazil (20) 1992–94	13.9	180.6

[a] WM = white men; WW = white women; AM = Asian men; AW = Asian women.

TABLE 2. Completeness of ascertainment as assessed through capture-recapture (CR) techniques

Country, period, references	Clinical studies	Routine surveillance system	CR method
Spain 1990–1993 (28)	Pulmonary tuberculosis	$15.85 \times 10^{(-5)}$	$34.81 \times 10^{(-5)}$
France 1994 (29)	Malaria	56.2%	78%
Pakistan 1994 (30)	Traffic accidents	4%	185/100 000
Spain (31)	Brucellosis	38±8	84%
Sweden (32)	Diabetes	3.20±0.08%	2.2–4.5%[a]
New Zealand 1990–1993 (33)	Childhood cancer	395	409[a]
Australia (34)	*Aedes aegypti*		13%
Denmark 1980–1994 (35)	Lupus erythematosus	3.6/100 000	21.7/100 000[a]
Italy 1990–1991 (36)	Celiac disease	0.47	0.84[a]
Italy 1996 (37)	Addison's disease	35–60/million	117/million
Australia, 1990–1996 (38)	Type 1 diabetes	17.8/100 000	99% complete
France 1990–1993 (39)	AIDS	47.6%	83.6%

[a] Based on three sources or more.

44 European centers covering a population of about 28 million children under 15 years of age.

Through the CR method, multiple sources of ascertainment were used to validate the completeness of LEA case registrations. The results confirm a very wide range of LEA incidence rates within Europe (3.2/100 000/year to 40.2/100 000/year).

The objective of this study was to estimate the incidence of LEAs in the general population of the municipality of Rio de Janeiro from 1992 to 1994, adjusting for under-ascertainment, and the incidence rates of LEAs performed on account of each of the following causes: peripheral vascular disease, diabetes mellitus, trauma, neoplasm, osteomyelitis, and gangrene.

MATERIALS AND METHODS

This retrospective study was carried out in the city of Rio de Janeiro, Brazil, from January 1, 1992 to December 31, 1994.

Over this period, the mean population of the city was 9 500 000 inhabitants. Patients submitted to a first or subsequent LEA due to a noncommunicable chronic condition (peripheral vascular disease, diabetes mellitus, neoplasm), acute infectious disease (osteomyelitis), and trauma were included in the study. For the purposes of this analysis, these entities were treated as if there were no overlap between them.

Data sources were categorized into three groups: an amputees register (S1), a limb-fitting center (S2), and a rehabilitation center (S3).

The amputee register established by the Rio de Janeiro State Health Secretariat requires that 23 of the city's hospitals, which represent more than 90% of all hospitals performing LEAs in the municipality, submit standardized information about all patients admitted. Patients with their first or subsequent LEA were identified through the amputee register.

Diagnoses were coded according to International Classification of Diseases (ICD-9) of the World Health Organization (WHO), and six groups of causes were included: peripheral vascular disease, diabetes mellitus, trauma, neoplasm, osteomyelitis, and gangrene.

Age, gender, place of residence, cause of the amputation, level of the amputation, and intervention dates were obtained from the records of each patient in each of the three data sources.

Additional information was available for specific sources. In source 1 (amputee register), such information included if the surgery was a "minor" or "major" amputation (see next para-

graph), if the LEA was the first or not, and the discharge evaluation, including death. Source 2 (limb-fitting center) provided data on the period elapsed between rehabilitation and the fitting of a prosthesis, and source 3 (rehabilitation center), on the time elapsed between the surgical procedure and the beginning of rehabilitation. Death certificates were reviewed in order to identify those patients listed in source 1 who died within the first 30 days after surgery.

An LEA was defined as "minor" if it was distal to the tarso metatarsal joint, and "major" if it was performed through or proximal to the tarso metatarsal joint. Reviewing operative mortality, defined as death within the first 30 days after the amputation, the study contemplated two situations: the inclusion of all patients listed in source 1, and the inclusion of all patients except those listed as dead postoperatively in the same source.

To estimate the incidence of LEAs using CR methods, three models were employed.

Model 1: Two sources—the amputee register (S1) and the limb-fitting center (S2) records—were examined, but 257 patients who were listed in S1 as dead postoperatively were excluded from the analysis.

Model 2: Three sources—the amputee register (S1), the limb-fitting center (S2), and the rehabilitation center records (S3)—were examined. All patients listed in S1 were included in the analysis.

Model 3: Three sources—the amputee register (S1), the limb-fitting center (S2), and the rehabilitation center records (S3)—were examined, but the 257 patients who were listed in S1 as dead postoperatively were excluded from the analysis. This was done in order to ensure greater accuracy, since the deceased patients in S1 or S2 are not recaptured.

Capture-recapture methods were adjusted for the undercount (41–44). When only two sources of ascertainment were used, Chapman's formula was applied (45).

Cases were cross-classified, whether they were present or absent in each

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source. The capture-recapture method was applied to estimate the number of cases missing in any of the sources.

A log-linear model was applied to estimate the incidence of LEAs when three sources were examined, with GLIM statistical software (46). Incidence rates were calculated per 100 000 population.

The diabetes-related incidence of LEAs was estimated using as the denominator the estimated diabetic population in Rio de Janeiro (approximately 232 000) in the middle of the study period (1992–1994), according to the Brazilian census (47).

The frequency of specific amputation rates for the types of problems (peripheral vascular disease, diabetes mellitus, trauma, neoplasm, osteomyelitis, and gangrene) was calculated using the EPI INFO program, version 6.02.

RESULTS

The cases of LEA identified by the three sources in Rio de Janeiro were: source 1 (23 hospitals), 1 191 cases per 100 000, or a total of 934 cases, excluding those who died postoperatively; source 2 (limb-fitting center), 157 amputated cases; source 3 (rehabilitation center): 34 cases.

Thirty-nine cases were common to S1 and S2. Applying Chapman's formula, the estimated number of LEAs in Rio de Janeiro over the study period was 3 555 (95% confidence interval [95% CI]: 2 784 to 4 362) (Figure 1).
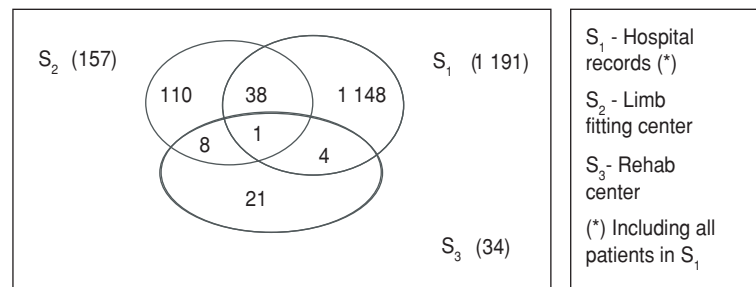
Figure 1 shows the estimated number of LEAs, excluding the 257 amputees who died postoperatively according to S1, as determined by the capture-recapture method using two sources of ascertainment (S1 and S2). The log-linear modeling approach to evaluate source dependencies is presented in Figures 2 and 3. As shown in Figure 2, the estimated number of LEAs is 5 040 when all 1 191 patients listed in S1 are included in the analysis. When cases are cross-classified between S1, S2, and S3, the estimated number of missing cases was 3 710 (Figure 2).

Figure 3 shows an estimated number of LEA of 3 954 cases, excluding those of the 257 dead patients listed in S1. When cases were cross-classified between S1, S2, and S3, the estimated number of missing cases was 2 881.

Using the estimated number of 3 954 LEAs in the numerator and the total population of the municipality of Rio de Janeiro in the middle of the 1992–1994 period in the denominator, the crude annual incidence rate of LEAs was 13.9 per 100 000 inhabitants.

The incidence rate of LEAs for the diabetic population was 180.6/100 000 diabetic patients. The routine surveillance system revealed an estimated annual incidence rate of LEAs of 5.4 per 100 000, and an estimated annual incidence rate of diabetics who underwent LEAs of 96.9 per 100 000.

Peripheral vascular disease, the most frequently observed condition as a cause of LEA, was present in 58.1% of all LEA cases, followed by diabetes mellitus, with 27.4%.

DISCUSSION

It may be argued that, in the case of LEAs, virtually 100% ascertainment should be obtained from either hospital or operating room records and that therefore the use of CR methodology is superfluous for estimating the incidence of LEAs. There are, however, several reasons that make this unlikely. They range from the incorrect coding or misplacement of patient records to the lack of access to such records, which can occur for a variety of reasons.

FIGURE 1. LEAs estimate with two sources of ascertainment, capture-recapture technology, Rio de Janeiro, 1992–1994
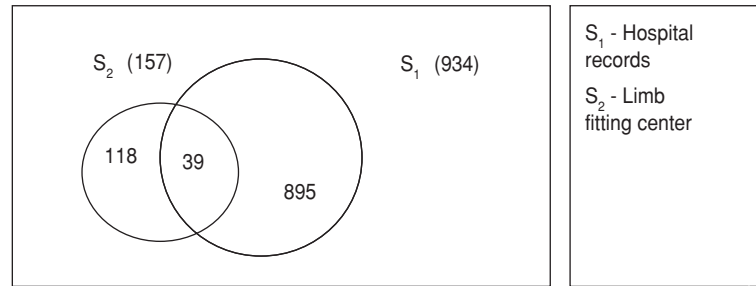
Dead patients excluded from S1
Observed number of cases = 1 077
Estimated number of cases = 3 555 (95% CI: 2 784 – 4 362)

FIGURE 2. LEAs estimate with three sources of ascertainment, capture-recapture technology, Rio de Janeiro, 1992–1994

Observed number of cases = 1 330
Estimated number of missing cases = $e^{8.219}$ = 3 710
Estimated number of cases = 3 710 + 1 330 = 5 040

FIGURE 3. LEAs estimate with three sources of ascertainment, capture-recapture technology, Rio de Janeiro, 1992–1994
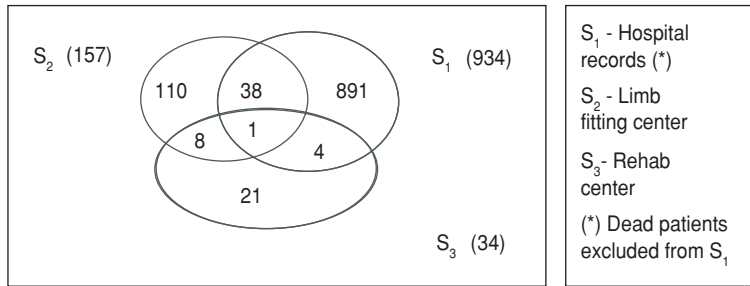
Observed number of cases = 1 073
Estimated number of missing cases = $e^{7.966}$ = 2 881
Estimated number of cases = 3 954

Data published over last three decades describe the incidence of LEAs, especially in North America, Europe and Australia. The present study is, to our knowledge, the first one in Latin America using the capture-recapture technique (48).

Standardization is urgently required in amputation data collection. Population-based numerator data currently do not indicate whether the left or right extremity was involved, or whether the LEA amputation was the first, second, or bilateral. Greater precision in data collection would enhance our understanding of the problem and improve our ability to target interventions to persons and groups at highest risk.

Capture-recapture methods allow for more accurate estimates and for monitoring diseases that are not easily identified through one or two primary sources (42–44).

Our objective in writing this report has also been to provide a standardized approach with CR techniques that will permit clinicians and researchers to estimate the incidence of LEA and to compare it across different regions.

Several methodological differences appear when reviewing the literature. Most studies measured LEA incidence in the general population (5, 11, 13, 14, 19). Only major amputations were included in the study from Sweden (15); two other studies described only the first LEA (11, 12), while two others reported subsequent LEAs as well (15, 18).

The Danish Amputation Register and Nationwide National Patient Register include all LEAs performed (25 767) during the period from 1978 through 1989. Based upon the code numbers in the WHO classification system (ICD-9), various etiologic categories (i.e., peripheral vascular disease, diabetes mellitus, neoplasm, and trauma) were extracted. However, the study failed to give incidence rates for the local population or standardized rates to their national population (18).

Data from Rio de Janeiro, Brazil, included the first or subsequent LEA. The general population of the city was used as the denominator when calculating the general LEA annual incidence rate (13.8 per 100 000). The diabetes-related incidence of LEAs was calculated with the diabetic population as the denominator (1 806 per 100 000). This revealed 13 times the risk of LEA among diabetics as compared to the nondiabetic population (20, 48).

CR methods merit greater use in Latin America within the field of epidemiology. They are useful not only for assessing the representativeness of surveillance systems, but also for identifying their inadequacies and localizing disease outbreaks.

According to the International Society for Disease Monitoring and Forecasting (45), there is a critical need for broad national and international monitoring of all serious diseases. Undercount and under-ascertainment are common to all disease-monitoring systems. Through procedures such as the capture-recapture technique, one can assess the degree of undercount and adjust disease counts and incidence rates accordingly. The methods employed in performing this study revealed findings similar to those of previous studies, demonstrating the feasibility of using the capture-recapture technique to estimate LEA incidence rates.

These findings suggest a very high LEA incidence rate in Rio de Janeiro as compared to that of other countries, such as Spain. They also identify diabetes mellitus as the second leading cause of LEAs in that city.

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RESUMEN

Método de captura-recaptura para estimar las tasas de amputación del miembro inferior en Río de Janeiro, Brasil

Objetivos. Estimar las tasas de amputación del miembro inferior (AMI) en individuos con vasculopatías periféricas, diabetes sacarina, traumatismos, neoplasias, osteomielitis o gangrena enfisematosa.

Métodos. Se utilizaron los registros regionales de amputados para estimar la tasa de AMI con el método de captura-recaptura (CR). Los datos se obtuvieron a partir de tres registros de amputados de Río de Janeiro: la fuente 1, con 1 191 casos de 23 hospitales; la fuente 2, con 157 casos de un centro de miembros artificiales, y la fuente 3, con 34 casos de un centro de rehabilitación. Los certificados de defunción de los amputados de la fuente 1 identificaron 257 muertes entre 1992 y 1994. Se investigaron dos modelos de CR utilizando las fuentes 2 y 3. Con el fin de evitar la sobreestimación de la tasa de AMI, en el análisis de los datos se aplicaron dos modelos: en uno se excluyeron los pacientes fallecidos que figuraban en la fuente 1, y en el otro se incluyeron.

Resultados. Excluyendo las 257 muertes, el número estimado de amputaciones en el municipio de Río de Janeiro entre 1992 y 1994 fue de 3 954, lo cual representa una incidencia anual media de 13,9 por 100 000 habitantes. En los pacientes diabéticos, la incidencia anual de AMI fue considerablemente mayor (180,6 por 100 000), lo cual representa un riesgo 13 veces mayor que en individuos sin diabetes. De acuerdo con el sistema de vigilancia habitual, las correspondientes tasas anuales de AMI fueron de 5,4 y 96,9, respectivamente. Combinando los datos de los tres registros, se identificaron 1 382 pacientes con AMI, cuyas causas se distribuyeron del siguiente modo: vasculopatías periféricas, 804 (58,1%); diabetes sacarina, 379 (27,4%); traumatismos, 103 (7,4%); osteomielitis, 44 (3,1%); gangrena, 36 (2,6%), y neoplasias, 16 (1,1%).

Conclusiones. En comparación con otros países, como España, estos resultados muestran una alta incidencia de AMI en Brasil, atribuible principalmente a las vasculopatías periféricas y a la diabetes sacarina.