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DIFFICULTIES IN COLLECTING DATA ON DUCTAL CARCINOMA *IN SITU* AT A POPULATION-BASED CANCER REGISTRY

Dificuldades na coleta de dados de carcinoma ductal *in situ* em um Registro de Câncer de Base Populacional

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ABSTRACT

Objective: To verify data-coding accuracy for ductal carcinoma *in situ* at the Goiânia population-based cancer registry in the Brazilian state of Goiás. **Methods:** Ecological time series analysis of cases coded as ductal carcinoma *in situ* in the state cancer database (ONCOSIS), considering data from the Goiânia population-based cancer registry, from 1994 to 2010. **Results:** Of 376 cases originally coded as ductal carcinoma *in situ*, 115 were excluded following a review of the pathology reports. These exclusions referred to cases of lobular carcinoma *in situ* (n=21), Paget's disease (n=4), invasive carcinoma (n=08), ductal carcinoma *in situ* associated with invasive carcinoma (n=14), microinvasive carcinoma (n=21), records on non-residents in Goiânia, and duplicated data (n=46). **Conclusion:** Many cases needed recoding and, as a consequence, altered the initial database. Standardizing pathology reports and training data collection staff are crucial steps to avoid omissions and errors when transcribing cases of ductal carcinoma *in situ* in a population-based cancer registry database.

KEYWORDS: DCIS; epidemiology; breast neoplasms; carcinoma in situ; carcinoma, intraductal, noninfiltrating.

RESUMO

Objetivo: Verificar a acurácia da codificação dos dados de carcinoma ductal *in situ* dentro do Registro de Câncer de Base Populacional de Goiânia, Goiás - Brasil. **Métodos:** Estudo ecológico de série temporal de casos codificados como carcinoma *in situ* da mama, pelo programa (ONCOSIS) do Registro de Câncer de Base Populacional de Goiânia, entre 1994 e 2010. Posteriormente realizou-se busca individual dos laudos histopatológicos de CDIS. **Resultados:** De 376 casos de CDIS, foram excluídos 115 casos após a revisão dos laudos anatomopatológicosas. As exclusões referem-se a carcinoma lobular in situ (21), Doença de Paget (4), carcinoma invasor (08); CDIS associado a carcinoma invasor (14); microinvasor (21), pacientes com endereço fora de Goiânia e dados duplicados (46). **Conclusão:** Há um grande número de casos que precisam ser recodificados, alterando o banco inicial. A padronização de laudos e o treinamento dos coletadores são etapas importantes para que não haja informações desconhecidas ao transcrever o CDIS para as fichas do RCBP.

PALAVRAS-CHAVE: DCIS; epidemiologia; neoplasias da mama; carcinoma *in situ*; carcinoma intraductal não infiltrante.

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INTRODUCTION

Earlier diagnosis of breast cancer in recent years has presented new challenges to breast specialists and pathologists. These professionals have been dealing with lesions that used to be rare in the past, which include premalignant or high-risk lesions, epithelial hyperplasia, and ductal carcinoma *in situ* (DCIS)[1].

The characteristics of DCIS include abnormal cell proliferation, predominantly in the terminal duct lobular unit, which consists of a lobule and its extralobular terminal duct, and a close involvement of true ducts[2]. There is also high risk of local recurrence in the absence of appropriate treatment[1].

Various questions have been raised with respect to DCIS, including its nomenclature. Some authors have suggested that the condition should be referred to as ductal intraepithelial neoplasia (DIN) rather than DCIS, with a range of subtypes and nuclear grades[3]. Nevertheless, the World Health Organization (WHO) rejected the proposal to change the term, since it failed to incorporate any new diagnostic criteria or to help reducing diagnostic disagreement between pathologists[4].

In general, references on carcinoma *in situ* in literature consist of partial reports or incomplete data in articles on invasive carcinoma, such as the statistics reported from international databases including the International Agency for Research on Cancer (IARC), which deals with breast cancer in general[5].

Increase in the number of DCIS cases. based on data from population-based cancer registries coded as Tis, N0, M0 according to the TNM classification, is noteworthy[6]. It is difficult to differentiate DCIS from atypical epithelial hyperplasia[4]; furthermore, microinvasive breast carcinoma is not treated as a separate entity from DCIS[7]. Since DCIS is a lesion that precedes invasive breast cancer, an initial study consisting of a detailed analysis of the database from the population-based cancer registry (PBCR) in the town of Goiânia would be of great relevance. The obtained information could be used to design further studies that could provide reliable data for healthcare interventions towards these women, ultimately improving treatment efficacy.

METHOD

This ecological study was conducted using data from the Goiânia PBCR, created in 1986 by the Goiás State Health Department, under the supervision of the Ministry of Health. Since 1994, the PBCR has been coordinated and administered by the Goiás Association for the Combat of Cancer. The PBCR collects and processes all new cases of cancer that occur every year in residents of the townships of Goiânia and Aparecida de Goiânia[5].

Data on DCIS cases that happened in Goiânia between 1994 and 2010 were reviewed in the study. To compile their database, the Goiânia PBCR actively collects data on DCIS diagnosed cases from all the pathology laboratories in this town.

The cases analyzed in this study had been included in the Integrated State System of Oncological Data (ONCOSIS dat-base). The data set referred to Goiânia between 1994 and 2010 and was coded according to the morphology (codes ending in 02 or 03) and location (ICD 10 and C-50.9 ICD-O-3). Later, an individual search was made for the pathology reports regarding DCIS cases.

All DCIS cases diagnosed between 1994 and 2010 in women living in the 739 km^2 area that constitutes the town of Goiânia were included in the study[6]. Following the analysis, cases in which women had only moved to these towns after diagnosis, cases with data collection biases and any cases in which DCIS was associated with invasive or microinvasive carcinoma were excluded from the study sample.

Ethics

This paper was filed and approved by the Ethics and Research Committee of the Proposed Institution, *Hospital das Clínicas/ Universidade Federal de Goiás* (UFG), and also referred to the Research Ethics Committee of the Co-participant Hospital Araújo Jorge/ACCG in compliance with resolution CNS 466/12, with the opinion of approval 350,312 on August 8, 2013.

RESULTS

Between 1994 and 2010, 376 cases of DCIS were registered. After reviewing the reports, 261 DCIS cases were maintained in the database, while 115 (30.6%) were excluded because they did not fulfill the inclusion criteria. The most common causes for exclusion were association with invasive carcinoma (n=14) and with a microinvasive tumor (n=21). Table 1 lists all the reasons for excluding the cases.

The classification of the histological subtypes of DCIS was available in 72.8% (190/261) of the reports included in the study, as shown in Table 2.

DISCUSSION

The PBCR of Goiânia in the state of Goiás, Brazil, has been evaluated as opportune, useful, and representative. In addition, its importance has been validated insofar as its contribution to the implementation of public policies regarding cancer prevention and control is concerned[8]. Nevertheless, considering the experience of the data collection staff in this PBCR, we found that a large number of cases diagnosed as invasive carcinoma had been transcribed to the PBCR registers as carcinoma *in situ*, thus altering the statistics on invasive breast cancer.

By definition, there can be no stromal invasion in DCIS; therefore, there can be no metastases[4]. The need of collecting data on

these non-invasive neoplasms has been questioned, and such data are often not adequately collected due to deficiencies in the training of the PBCR staff.

The increasingly common use of mammography as a screening tool for breast cancer early detection has led to an increase in the number of cancer cases detected at initial stages. However, most reports do not refer to microinvasive carcinoma as a separate entity, but include this diagnosis in the earliest category of invasive disease (e.g. T1a lesions)[8]. Microinvasive carcinoma is pathologically defined as invasion ≤1 mm with its origin in a, sometimes, quite extensive DCIS[9,10]. These tumors represented 18.3% of the cases excluded from this study.

Table 1. Distribution of the excluded cases with data collection biases or with incomplete data.

Database initial value (population-based cancer registry of Goiânia) Ductal carcinoma *in situ*	376 n	100 %
Deleted data		
Carcinoma lobular *in situ* data and Paget's disease included according to topographical and morphological classification in ONCOSIS (population-based cancer registry of Goiânia).	25	6.6
Microinvasive	21	5.5
DCIS associated with infiltrating ductal carcinoma	07	1.9
DCIS associated with invasive ductal carcinoma	07	1.9
Infiltrating ductal carcinoma	01	0.3
Invasive carcinoma (no other specifications)	05	1.3
Lobular invasive carcinoma	01	0.3
Tubular Carcinoma	01	0.3
Patients residing outside Goiânia	36	9.5
Duplicated data	10	2.6
Cervical cancer	01	0.3
Number of ductal carcinoma in situ cases after analysis	261	

Table 2. Classification of histologic subtypes of ductal carcinoma *in situ*, according to pathology report (261 cases).

Histological subtypes of ductal carcinoma *in situ*	n	%
Apocrine	1	0.3
Solid	9	2.4
Papillary	17	4.5
Comedo	61	16.2
Cribriform	32	8.5
Mixed	70	18.6
Cases classified in the pathology reports	190	72.8
Without specification in the pathology reports	71	27.2

Differences in pathology reports, especially in the case of lengthy, non-standardized texts, not only make interpretation errors by the data collection staff more likely but may also account for biases in the surgeon's assessment, ultimately affecting the optimum surgical plan.

If invasion is present, the lesion, depending on its size, could consist of an invasive ductal carcinoma with an extensive ductal component, which would be composed of the remaining cells that had not acquired the capacity to invade[11]. However, such cases are being transcribed to the PBCR database as "*in situ*" due to the data collection staff's lack of knowledge.

In some of the analyzed cases, an immunohistochemical study was required to enable a conclusion to be reached regarding a diagnosis of DCIS. Nonetheless, even when this report was not attached or was inconclusive, with no further follow-up, these cases were transcribed as "*in situ*" on the registers. In other situations, in reports containing detailed descriptions, the first piece of information found was a DCIS, followed by information on an invasive carcinoma, which could have remained unnoticed by the surgeon and by the data collection staff.

Another piece of information that is difficult to find in DCIS reports concerns the histological subtype. Of the 261 evaluated reports, 27.2% of the DCIS cases were not classified as to their histological subtype. This was justified by the restricted size of the fragment sent for analysis, which did not permit its architecture to be evaluated[12]. Table 2 shows the DCIS cases and their histological types according to the evaluated reports.

At first glance, the term "DCIS with an area of microinvasion of x millimeters" gives the false impression that the DCIS is the main lesion, possibly allowing more important information on invasive or microinvasive lesions to go unnoticed. Therefore, we suggest that the lesion with the greatest aggressive potential be described firstly. After reporting is standardized, the data collection staff should then be trained to guarantee that data are clearly understood when DCIS cases are transcribed to the PBCR registers.

The standardized routine for the data collection on all types of cancer established to meet the criteria defined by the National Cancer Institute and by the IARC is well known. The intention in this study is to collaborate with the registry, which has been the source of data for many epidemiological studies that have provided a basis for health actions. This pioneering study should cause a reflection both in the staff of population-based cancer registries, when transcribing the data to the forms, and in the pathologists when composing the histopathology reports, keeping in mind the importance of the accuracy of these data in healthcare services.

CONCLUSIONS

As shown in the present study, the lack of standardization in pathology reports led to many cases of DCIS having to be recorded, thus altering the initial database and affecting statistics on invasive breast cancer. The way these reports are completed needs to be standardized, with objective and concise descriptions regarding the DCIS diagnosis. They should be simple to read and should enable professionals, including the data collection staff at the PBCR, to immediately identify whether the case in question indeed refers to a DCIS or whether it consists of an invasive or microinvasive tumor with an extensive intraductal component.

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