Accuracy of kidney cancer diagnosis and histological subtype within Canadian cancer registry data

Jeffrey G. Himmelman, MD[1]; Jennifer Merrimen, MD[2]; Kara Matheson, MSc[3]; Chris Theriault, P. Eng[3]; Lori A. Wood, MD[1,4]

[1]Department of Urology, Dalhousie University, Halifax, NS; [2]Department of Pathology and Laboratory Medicine, Dalhousie University, Halifax, NS; [3]Research Methods Unit, Nova Scotia Health Authority; [4]Department of Medicine, Dalhousie University, Halifax, NS; Canada

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Abstract

Introduction: Provincial/territorial cancer registries (PTCRs) are the mainstay for Canadian population-based cancer statistics. Each jurisdiction captures this data in a population-based registry, including the Nova Scotia Cancer Registry (NSCR). The goal of this study was to describe data from the NSCR regarding renal cell carcinoma (RCC) pathology subtype and method of diagnosis and compare it to the actual pathology reports to determine the accuracy of diagnosis and histological subtype assignment.

Methods: This retrospective analysis included patients diagnosed with RCC in the NSCR from 2006–2010 with an ICD-O-3 code C64.9 seen or treated in the largest NS health district. From the NSCR, method of diagnosis and pathological diagnosis was recorded. All diagnoses of non-clear-cell RCC (nonccRCC) from NSCR were compared to the actual pathology report for descriptive comparison and reasons for discordance.

Results: 723 patients make up the study cohort. 81.3% of patients were diagnosed by nephrectomy, 11.1% radiography, 6.9 % biopsy, and 0.7% autopsy. By NSCR data, 52.8% had clear-cell (ccRCC), 20.5% RCC not otherwise specified (NOS), 12.7% papillary, 4% chromophobe, and the rest had other nonccRCC subtypes. By pathology reports, 69.5% had clear-cell, 15% papillary, 5% chromophobe, only 2.7% RCC NOS. There was a discordance rate of 15.4% between NSCR data and diagnosis from pathology report. Reasons for discordance were not enough information by the pathologist in 45.5%, misinterpretation of report by data coder in 22.2%, and true coding error in 32.3%.

Conclusions: When using PTCR for RCC incidence data, it is important to understand how the diagnosis is made, as not all are based on pathological confirmation; in this cohort 11% were based on radiology. One must also be aware that clear-cell and non-clear-cell subtypes may differ between the PTCR data and pathology reports. In this study, ccRCC made up 52.8% of the registry diagnoses, but increased to 69.6% on pathology report review. Use of synoptic reporting and ongoing education may improve accuracy of registry data.

Introduction

Cancer registries are the mainstay for population-based cancer statistics, including incidence and cancer type. In Canada, provincial and territorial cancer registries (PTCRs) capture cancer statistics, which in our jurisdiction is the Nova Scotia Cancer Registry (NSCR). Each PTCR contributes their data to the Canadian Cancer Registry maintained by Statistic Canada and is used to produce standardized and comparable statistics for cancer incidence and survival data.[1]

Renal cell carcinoma (RCC) accounts for 2–3% of all malignant neoplasms and is the most lethal of urologic malignancies.[2] RCC is divided into many different subtypes, but is often dichotomized into clear-cell and non-clear-cell RCC (nccRCC). nccRCC is made up of a large number of different cancers with different pathological features, genetic mutations, and clinical outcomes.[3] Given the variation in presentation, treatment, and outcomes, it is important that registries document not only cases of RCC, but also accurate pathological subtypes. It is also important to note that recently the Kidney Cancer Research Network of Canada (KCRNC) ranked the management of advanced nccRCC as its top priority among all proposed research topics. This starts with having an accurate assessment of the number and subtype of nccRCC cases in Canada.

There were three major goals of this study. The first was to assess how cases of RCC in the NSCR were diagnosed. The second was to describe the pathology subtypes of RCC in the NSCR and compare these with actual pathology reports in order to assess concordance rates of RCC subtype between the NSCR and actual pathology reports. The third goal was to understand why there might be discordance between the NSCR and the actual pathology reports.

Methods

Approval from the Nova Scotia Health Authority (NSHA) research ethics board was obtained. This study assessed the

NSCR for all diagnosis of RCC from 2006–2010 within the largest health district in NS, where the vast majority of RCC care in the province takes place. Cases were identified by searching the NSCR for those diagnosed with topographical ICD-O-3 code 64.9.[4] This code is used to describe malignant neoplasms of the kidney excluding the renal pelvis.

A database was created and variables, including date of diagnosis, method of diagnosis (radiographical, tissue from nephrectomy or partial nephrectomy, biopsy or fine needle aspirate, or autopsy), and pathology of neoplasm from both the NSCR and the pathology reports were recorded. If the diagnosis was made based on radiography, there were no pathology reports to review and assess for concordance. If the NSCR pathology subtype was coded as clear-cell, it was assumed to be correct and those pathology reports were not reviewed. If the NSCR pathology subtype was nccRCC, all of the original pathology reports were reviewed. During this time frame, the pathologists based their classification on the WHO pathological classification system.[5] If there was disagreement between the NSCR pathology classification and the actual pathology report this was recorded and the reason for the discordance was classified as due to: true coding error, misinterpretation of the pathology report by the data abstracter, and not enough information provided by the pathologist in the "final diagnosis" section of the report. The reason for discordance was determined and agreed upon by two of the investigators (JH, LW).

Statistics

Variables were entered into a Microsoft Access database. Clinical characteristics were summarized using means and standard deviations for continuous variables and frequency and counts for categorical variables. Data was analyzed using SAS STAT software version 9.3 (SAS Institute, Cary NC, U.S.).

Results

Between 2006 and 2010, 723 patients were identified in the NSCR with a diagnosis of malignant neoplasm of the kidney. The incidence was consistent over the five years, ranging from 141 to 149 cases per year. Baseline demographics are detailed in Table 1. The median age of diagnosis was 63.7 years and 61.8% were male. Diagnosis was made by nephrectomy/partial nephrectomy in 588 (81.3%), biopsy/aspirate in 50 (6.9%) and autopsy in 5 (0.7%). Of the 723 cases, 81 (11.2%) were made solely by radiographic diagnosis.

In all 723 patients in the NSCR, the most common pathological subtype was clear-cell, seen in 382 cases (52.8%), followed by RCC not otherwise specified (NOS) in 149 cases (20.6%), papillary in 92 cases (12.7%), chromophobe in 29 cases (4.0%), and other in 71 cases (9.8%), as shown in Table 1. The 71 other cases included non-small-cell carcinoma, lymphoma, mucinous and spindle cell, carcinoma NOS, oxyphillic carcinoma, hemangiosarcoma, malignant nephroma, neuroendocrine and collecting duct carcinoma. In the 81 cases diagnosed on radiography alone, 64 (79%) were coded as RCC NOS and 17 (21%) were classified as malignant neoplasm. Both of these would be considered nccRCC.

Table 1. Baseline characteristics of NSCR cases from 2006–2010

	n (%)
Total cases	723
Gender male	447 (61.8)
Method of diagnosis	
Nephrectomy	588 (81.3)
Radiography	80 (11.1)
Biopsy	50 (6.9)
Autopsy	5 (0.7)
NSCR pathology subtype	
Clear-cell	382 (52.8)
RCC not otherwise specified	149 (20.6)
Papillary	92 (12.7)
Chromophobe	29 (4.0)
Other*	71 (9.8)

*Included non-small cell carcinoma, lymphoma, mucinous and spindle cell, carcinoma not otherwise specified, oxyphillic carcinoma, hemangiosarcoma, malignant nephroma, neuroendocrine, and collecting duct carcinoma. NSCR: Nova Scotia Cancer Registry; RCC: renal cell carcinoma.

The remainder of the results section pertains only to the 642 NSCR cases with the diagnosis of RCC made with tissue. Of these, 260 cases were considered nccRCC and the actual pathology reports were reviewed. After this review, the breakdown of pathological subtype included clear-cell in 447 cases (69.5%), papillary in 96 cases (15.0%), chromophobe in 32 cases (5.0%), multilocular cystic clear cell in 21 cases (3.3%), RCC NOS in 17 cases (2.7%), and other in 29 cases (4.5%), as detailed in Table 2.

Table 2. Comparison of NSCR subtype to pathology subtype excluding those diagnosed by radiography

	NSCR pathology, n (%)	Pathology report, n (%)
Clear-cell	382 (59.5)	447 (69.5)
Papillary	92 (14.3)	96 (15.0)
RCC NOS	84 (13.1)	17 (2.7)
Chromophobe	29 (4.5)	32 (5.0)
Multilocular cystic	11 (1.7)	21 (3.3)
RCC sarcomatoid	16 (2.5)	5 (0.7)
Adenocarcinoma	11 (1.7)	0 (0.0)
Unclassified RCC	0 (0.0)	5 (0.7)
Malignant neoplasm	3 (0.5)	0 (0.0)
Other*	14 (2.2)	19 (3.0)
Total	642	642

*Included non-small cell carcinoma, lymphoma, mucinous and spindle cell, carcinoma not otherwise specified, oxyphillic carcinoma, hemangiosarcoma, malignant nephroma, neuroendocrine, and collecting duct carcinoma. NOS: not otherwise specified; NSCR: Nova Scotia Cancer Registry; RCC: renal cell carcinoma.

The biggest changes in pathology based on reports compared to NSCR were an increase in clear-cell from 382 cases to 447, decrease in RCC NOS from 84 cases to 17, and decrease of RCC sarcomatoid from 16 to five cases. There was discordance between the NSCR and the actual pathology in 99 cases (15.4%). The reason for discordance was not enough information provided by the pathologist in the "final diagnosis" in 45 cases (45.5%), true coding error by the coder in 32 cases (32.3%), and misinterpretation of the report by the data abstracter in 22 cases (22.2%). Discordance rates were highest in autopsy cases, with 40% discordance, followed by biopsy/aspirate with 20.4% and nephrectomy with 14.7%.

Discussion

This study was a retrospective review assessing the accuracy of the NSCR for diagnosis of RCC and its subtypes for cases diagnosed between 2006 and 2010. Review revealed that 81 of 723 cases (11.2%) were diagnosed based on imaging characteristics alone and thus no conclusions can be drawn about the true pathology. Up to 20% of enhancing renal masses less than 4 cm are found to be benign on pathological assessment.[6] Therefore, the NSCR may overestimate cases of malignant RCC. Since these radiologically diagnosed RCCs were either classified as RCC NOS or malignant neoplasm, both of which would be considered a nccRCC, the NSCR data would appear to overestimate the incidence of nccRCC in the population. While it is accepted that population-based cancer registries across the world permit the registration of non-pathologically confirmed diagnosis in a variety of circumstances, including radiological and clinical findings, not all may be aware of this. This study allows us to actually quantify the incidence of this over a five-year period from a single population.

In the NSCR, the breakdown by RCC subtype differed from published reports. Most reports estimate clear-cell as comprising 80%, papillary 10%, chromophobe 5%, and rare variants making the final 5%.[5-7] Review of the NSCR found clear-cell made up only 52.8% of the RCC subtypes and NOS made up 20.5%; however, when the cases diagnosed by radiography were excluded and the pathology obtained from pathology reports was reviewed, clear-cell increased to 69.5%, followed by papillary at 15% and chromophobe 5%. Therefore, although initial assessment of the NSCR showed different results from other series, once it was limited to only those with pathological diagnosis, the subtype breakdown was in agreement with the published series. These results reinforce that if one is using PTCR RCC incidence and pathological subtype data, it is important for clinicians and researchers to understand the diagnostic confirmation methods and classification methods.

Discordance in pathology subtype between the NSCR and pathology reports was seen in 99 of the 642 cases where tissue was used for diagnosis (Table 3). The most common reason for discordance was that there was not sufficient information provided by the pathologist in the final diagnosis portion of the report. For example, there were several reports in which the pathologist favoured a certain subtype and this was stated in the details of the report, but because they were not absolutely certain, the "final diagnosis" was made as RCC NOS. The second most common reason for discordance was the data abstracters misinterpreting the pathology report. For example, there were cases where the pathologist used the term "conventional RCC" and these were coded in the registry as RCC NOS. An example of a true coding error would be one subtype mistakenly replaced for another despite a clear diagnosis on the pathology report.

Table 3. Reason for discordance between NSCR and pathology reports

	Reasons for discordance, n (%)		
Total number of discordant pathology	Not enough information by pathologist	Misinterpretation of report by data coder	True coding error
99	45 (45.5)	22 (22.2)	32 (32.3)

NSCR: Nova Scotia Cancer Registry.

The classification of all neoplasms, including RCC, evolves over time as our understanding of their behaviour and molecular characteristics expands. Over the last 10 years, many rare renal neoplasms that were previously classified as RCC NOS are now diagnosed as a specific entity. These changes are seen if you compare the WHO classification of renal neoplasms in 2004[5] to the WHO classification of renal neoplasms in 2016.[8] These major classification changes occur after enough new information emerges from a variety of studies to warrant a consensus conference to review the classification system used.[9] If PTCRs are not aware of the changes in the RCC classification system or if there is a lag time between updates, these neoplasms will continue to be recorded inaccurately.

We propose a number of ways that the accuracy could be improved. First, all RCC diagnosed by radiological imaging alone should be classified in the same way. Second, improvement would come with ongoing education for data abstracters and coders. For example, it is imperative that when different terms like "conventional RCC" are used, data abstracters are informed that this is synonymous with clear-cell. We feel the adoption of synoptic reporting, along with education to pathologists, would strongly improve the accuracy of PTCR data by limiting interpretation required by data abstracters. Finally, it is important that there is alignment between most recent ICD-O classification system and the most up-to-date International Society of Urologic Pathology classification system to allow accurate coding of RCC subtype pathology.[8,9]

Conclusion

Knowing the correct diagnosis and pathological subtype of RCC is imperative for managing RCC patients, as well as improving care through research and innovation. This study highlights that the NSCR diagnose 11% of their RCC based on radiological imaging alone. As well, due to the inclusion of cases diagnosed by imaging and discordance between the recorded data and the actual pathology reports, one must be aware that the registry data overestimates the incidence of nccRCC. These results may apply to other PTCRs depending on the rate of synoptic reporting and communication between clinicians and registries in any given jurisdiction. This research highlights the need for active and ongoing discussions between the registry community and the clinicians/researchers using and relying on this data.

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Correspondence: Dr. Jeffrey G. Himmelman, Department of Urology, Dalhousie University, Halifax, NS, Canada; jeff.himmelman@dal.ca