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The database of the Danish Renal Cancer Group

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Aim of the database: The main purpose of the database of the Danish Renal Cancer Group (DaRenCaData) is to improve the quality of renal cancer treatment in Denmark and secondarily to conduct observational research.

Study population: DaRenCaData includes all Danish patients with a first-time diagnosis of renal cancer in the Danish National Pathology Registry since August 1, 2010.

Main variables: DaRenCaData holds data on demographic characteristics, treatments, and pathology collected through linkage to central registries and online registration of a few clinical key variables. Eight quality indicators have been selected for monitoring treatment quality and outcome after renal cancer.

Descriptive data: The incidence of renal cancer in Denmark has increased from 12.7 per 100,000 population-years in 2010–2011 to 15.9 per 100,000 population-years in 2014–2015. A total of 3,977 Danish patients with renal cancer have been enrolled in the database in the period August 1, 2010–July 31, 2015. The completeness of data registration has increased substantially since the first years of the database. A tendency toward smaller and less advanced tumors, less invasive surgery, and a shorter hospital stay was observed, while the postoperative morbidity and mortality remained stable. Concurrently, the 1-year survival has improved and was 84.1% in 2014–2015.

Conclusion: DaRenCaData provides valuable information on quality of and outcome after renal cancer treatment. Efforts to improve collection and registration of data are ongoing.

Keywords: kidney cancer, database, clinical quality, indicators, incidence, survival, observational research

Background

Renal cancer accounts for 3%–4% of new cancer cases in adults.^{1–3} Data from the Nordic cancer registry NordCAN show that renal cancer in Denmark in the years 2009–2013 comprised 2.5% of all new male and 1.4% of all new female cancer cases.³ Survival after renal cancer has been lower in Denmark compared to the other Nordic countries for decades.^{3,4}

The multidisciplinary Danish Renal Cancer Group (DaRenCa) was established in 2006 following a national plan to improve survival of cancer for all Danish patients.⁵ DaRenCa is a group of academic experts representing urology, oncology, pathology, radiology, nuclear medicine, and epidemiology dealing with cancer originating from the renal parenchyma. The aim of DaRenCa is to improve the renal cancer survival in Denmark, and the group is responsible for developing national guidelines for diagnosis and treatment of renal cancer. The nationwide database of the DaRenCa

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(DaRenCaData) was established in 2010 as one of the other tasks of the group.

Aim of the database

The main purpose of the database is to improve the clinical quality of renal cancer treatment in Denmark by monitoring selected processes and outcome after renal cancer treatment and secondarily to provide an important data source for observational research.

Study population

DaRenCaData includes all patients with a first-time diagnosis of renal cancer in Denmark since August 1, 2010. The patients are identified by the first-time registration of a diagnosis of renal cancer in the Danish National Pathology Registry to secure verification by histology or cytology.⁶ Through the Danish National Patient Registry, the database additionally identifies all surgical treatment procedures performed on patients with renal cancer.⁷

Main variables

The variables in the database are obtained from two main sources: through data linkage from central national registries and through data registered online in a web-based form by the treating clinicians. This online registration form is part of a common platform for the five urooncological databases in Denmark.⁸

Information on sex, age, and vital status is retrieved from the Danish National Civil Registry.⁹

Data on specific surgical and oncological treatment as well as comorbidity are retrieved from the National Patient Registry.⁷ These data are part of the routine registration done in connection with procedures performed during hospitalization and outpatient treatment at hospitals. The surgical procedures are registered as radical or partial nephrectomies or ablative procedures (cryotherapy and radio frequency ablation), and whether the procedures are performed laparoscopically or open. Variables describing the surgical quality include information on the length of hospital stay, 30-day postoperative mortality, and 30-day postoperative morbidity. Information on specific oncological treatment modalities is also retrieved.

Systematized Nomenclature of Medicine codes for the histological subtype of cancer, Fuhrman grade, Leibovich score, pT-stage, and type of specimen are drawn from the Danish National Pathology Registry.⁶

Additional data from the web-based form include: civil registration number as patient identifier, date of diagnosis, main debut symptoms (incidentally found tumor, hematuria,

nonspecific symptoms), and results of blood tests performed at the time of diagnosis (hemoglobin, C-reactive protein, ionized calcium, lactate dehydrogenase, serum sodium, neutrophils). The database is not collecting data on lifestyle factors. In case of locoregional or metastatic recurrent disease, a special recurrence form is used.

Eight quality indicators with recommended standards based on experience and available literature have been selected for monitoring the clinical quality of renal cancer treatment in Denmark. These indicators collected once a year include description of the treatment of renal cancer (process indicators) as well as description of outcome (result indicators).

Data quality

As most data come from preexisting registries and only a few data are registered manually in the web-based forms, it should be possible to achieve a high completeness of data, obviously depending on the quality of these data.

All urological, surgical, oncological, and other departments diagnosing and treating patients with renal cancer register online in the web-based form at the time of diagnosis. This form was filled in for 89.0% of all new renal cancer cases during the last study period August 1, 2014–July 31, 2015, with a variation between departments treating more than ten patients between 37.5% and 98.6%. This registration has improved over the years: 65.4% in 2010–2011, 69.3% in 2011–2012, 82.3% in 2012–2013, and 84.4% in 2013–2014. Ten urological departments diagnosed more than ten new patients with kidney cancer in 2014–2015. Four of these had a high and stable registration rate during all 5 years with a mean between 88.0% and 95.9%. Five improved their registration substantially, one from 14.5% to 87.7% and another from 52.9% to 95.0%. Only one department showed a decrease in registration from 76.2% to 37.5%.¹⁰

As DaRenCaData is a newly established database with only 5 years of data collection to date, results and data from the initial years should be interpreted with caution. During the recent years, the algorithms for identification of patients with incident renal cancer in the pathology registry have been optimized. As a result, the data completeness and validity have improved over time. In particular, the algorithms have been redefined, and data from five larger hospitals diagnosing and treating patients with renal cancer have undergone a detailed validation of data concerning the surgical procedures and pathological data. This validation revealed that the main reason for incomplete data was incorrect or incomplete registration of some of the clinical and pathological data. Validation of data on oncological treatment is currently

Table 1 Characteristics of the patient population in DaRenCaData

Characteristics	Year of diagnosis (August 1–July 31)				
	2010–2011	2011–2012	2012–2013	2013–2014	2014–2015
New cases	705	724	769	880	899
New cases per 100,000 citizens, n	12.7	13.0	13.7	15.6	15.9
Women, n (%)	230 (32.6)	242 (33.4)	267 (34.7)	305 (34.7)	313 (34.8)
Men, n (%)	475 (67.4)	482 (66.6)	502 (65.3)	575 (65.3)	586 (65.2)
Age at diagnosis (years)					
Median	65	64	66	67	67
25th percentile	57	56	58	57	57
75th percentile	72	71	73	73	74
Comorbidity at diagnosis^a					
Score 0, n (%)	354 (50.2)	394 (54.4)	412 (53.6)	463 (52.6)	487 (54.2)
Score 1–2, n (%)	242 (34.3)	218 (30.1)	242 (31.5)	278 (31.6)	277 (30.8)
Score 3+, n (%)	109 (15.5)	112 (15.5)	115 (15.0)	139 (15.8)	135 (15.0)
	Year of surgery (August 1–July 31)				
	2010–2011	2011–2012	2012–2013	2013–2014	2014–2015
Surgical procedures, n	591	644	656	749	807
Median age at surgery	64	64	65	65	66

Notes: ^aGiven as Charlson comorbidity index score.¹⁴ Data from DaRenCa, a subgroup of Dansk Urologisk Cancer Gruppe.¹¹

Abbreviation: DaRenCaData, database of the Danish Renal Cancer Group.

ongoing. Further validation studies will ensure an even higher completeness and validity of all data in DaRenCaData in the future.

Main results

During the period August 1, 2010–July 31, 2015, 3,977 patients with renal cancer have been enrolled in the database.¹¹ Over this period, incidence has increased in total

number of new cases and number of new cases per 100,000 citizens (Table 1).¹²

The eight quality indicators as well as results from 2010 to 2015 are summarized in Table 2.^{10,11}

There has been a tendency toward use of more minimal invasive procedures with lesser surgical traumas. The proportion of radical nephrectomies performed laparoscopically has increased from 60.0% in 2010–2011 to 66.4% in

Table 2 Quality indicators and indicator results in DaRenCaData

Indicator	Standard (%)	Type	Year of diagnosis (August 1–July 31)				
			2010–2011 ¹⁰	2011–2012 ¹¹	2012–2013 ¹¹	2013–2014 ¹¹	2014–2015 ¹¹
1a Proportion of localized disease (T1–2, N0/x, M0/x) at diagnosis	≥65	Process	51.2	50.0	52.5	54.3	54.8
1b Proportion of localized disease (T1a, N0/x, M0/x) at diagnosis	Not yet defined	Process	20.0	21.0	23.7	29.8	27.6
2a Proportion of radical nephrectomies for local disease (T1–2) performed laparoscopically	≥85	Process	65.3	75.9	74.4	76.0	76.4
2b Proportion of radical nephrectomies performed laparoscopically	≥65	Process	60.0	62.2	64.9	68.2	66.4
3 30-day morbidity	≤5	Result	4.3	4.3	3.4	4.2	4.4
4 Recurrence ^a within 3 years	≤25	Result	28.9	29.2			
5 30-day mortality	≤0.5	Result	0.7	1.6	0.5	0.7	0.4
6a 1-year observed survival	≥80	Result	81.3	81.9	83.4	84.1	
6b 3-year observed survival	Not yet defined	Result	68.2	69.9			
7 Hospital stay ≤3 days after an endoscopic or ablative procedure	≥85	Result	68.1	70.9	75.2	75.3	80.1
8 Proportion of T1a tumor treated by radical nephrectomy	≤10	Result	46.7	35.0	25.1	26.8	17.4

Note: ^aRecurrence: locoregional or metastatic recurrent disease. TNM, the TNM system for describing the anatomical extent of disease are based on T (the extent of the primary tumour); N, the absence or presence of regional lymph node metastasis; M, the absence or presence of distant metastasis.

Abbreviation: DaRenCaData, database of the Danish Renal Cancer Group.

2014–2015.¹¹ The proportion of nephron-preserving procedures (partial nephrectomy and ablation) increased from 22.9% in 2010–2011 to 43.5% in 2014–2015, and the proportion of patients with T1a (≤ 4 cm) cancers who underwent a radical nephrectomy decreased from 46.7% in 2010–2011 to 17.4% in 2014–2015.¹¹ The proportion of patients who were hospitalized for 3 days or less after an endoscopic or ablative procedure increased from 68.1% to 80.1% during the last 5 years, while the postoperative morbidity and mortality was stable during the last 5 years.¹¹

Tumor size at diagnosis tends to be smaller and less advanced in the most recent years. The number of radical and partial nephrectomies with pT1a tumors increased from 17.6% in 2011–2012 to 29.8% in 2014–2015, while the number of patients with pT3–4 tumors decreased from 45.0% in 2011–2012 to 29.8% in 2014–2015.¹¹

Information on the specific histological subtype, which is an important prognostic factor and used for determining later treatment of metastatic disease, was recorded for 53% of the newly diagnosed patients in 2010–2011, 74.5% in 2011–2012, 87.5% in 2012–2013, 83.8% in 2013–2014, and 85.9% in 2014–2015.¹¹

The 1-year observed survival after the diagnosis of renal cancer increased from 81.3% for patients diagnosed in 2010–2011 to 84.1% in patients diagnosed in 2014–2015.¹¹ The 3-year observed survival was 68.2% for patients diagnosed in 2010–2011, and 69.9% for patients diagnosed in 2011–2012.¹¹

Follow-up

All patients enrolled in the database are followed until death or emigration with collection of data comprising surgical and medical oncological treatment as well as data on the date and type of recurrence.

Data suggested to be included during follow-up in the future are, among others, the development of a new primary renal cancer in the residual and/or contralateral kidney and development of renal insufficiency after renal surgery.

Research

No research projects have evolved until now, but in the coming years, the database will be provide the basis for and conduct several observational studies of Danish patients with renal cancer.

Administrative issues and funding

DaRenCaData is funded by the Danish Regions by the Danish Clinical Registries as one of more than 60 national clinical quality databases in Denmark.¹³ Epidemiological,

statistical, and technical support is provided by two regional registry support centers in Denmark (The Registry Support Center of Epidemiology and Biostatistics [North] and The Registry Support Center of Clinical Quality and Health Informatics [West]). The database is headed by a steering group representing the specialties in DaRenCa supplied by biostatistics and quality improvement. An annual report is published each year covering the period from August 1 of the first year to July 31 of the next year.¹¹ The publication follows a national audit by the steering group of national-, regional-, and institutional-based results. After publication, the regions and departments perform a local audit of the results for their own organization.

Conclusion

DaRenCaData was established in 2010 to provide valid information on renal cancer statistics.

Data from the first 5 years of the database suggest an improvement of survival, a tendency toward smaller and less advanced tumors at the time of diagnosis, and an increased use of less invasive surgery.

It is important to note that the database is relatively young, and the data from the first years should be interpreted with caution. Nevertheless, the completeness of the online registration has improved substantially during these first 5 years. Effort to improve data completeness and validity is ongoing.

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Disclosure

The authors report no conflicts of interest in this work.

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