

The Danish Bladder Cancer Database

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Aim of database: The aim of the Danish Bladder Cancer Database (DaBlaCa-data) is to monitor the treatment of all patients diagnosed with invasive bladder cancer (BC) in Denmark.

Study population: All patients diagnosed with BC in Denmark from 2012 onward were included in the study. Results presented in this paper are predominantly from the 2013 population.

Main variables: In 2013, 970 patients were diagnosed with BC in Denmark and were included in a preliminary report from the database. A total of 458 (47%) patients were diagnosed with non-muscle-invasive BC (non-MIBC) and 512 (53%) were diagnosed with muscle-invasive BC (MIBC). A total of 300 (31%) patients underwent cystectomy. Among the 135 patients diagnosed with MIBC, who were 75 years of age or younger, 67 (50%) received neoadjuvant chemotherapy prior to cystectomy. In 2013, a total of 147 patients were treated with curative-intended radiation therapy.

Descriptive data: One-year mortality was 28% (95% confidence interval [CI]: 15–21). One-year cancer-specific mortality was 25% (95% CI: 22–27%). One-year mortality after cystectomy was 14% (95% CI: 10–18). Ninety-day mortality after cystectomy was 3% (95% CI: 1–5) in 2013. One-year mortality following curative-intended radiation therapy was 32% (95% CI: 24–39) and 1-year cancer-specific mortality was 23% (95% CI: 16–31) in 2013.

Conclusion: This preliminary DaBlaCa-data report showed that the treatment of MIBC in Denmark overall meet high international academic standards. The database is able to identify Danish BC patients and monitor treatment and mortality. In the future, DaBlaCa-data will be a valuable data source and expansive observational studies on BC will be available.

Keywords: bladder cancer, cystectomy, neoadjuvant chemotherapy, curative-intended radiation therapy

Aim of database

Patients diagnosed with invasive bladder cancer (BC) in Denmark are treated according to the national guidelines at one of the five uro-oncological centers. The aim of the Danish Bladder Cancer Database (DaBlaCa-data) is to monitor treatment and general survival of patients diagnosed with BC in Denmark. The goal of the database is to provide standards of the highest level of clinical evidence based on expert knowledge in the area.

To guide the selection of quality indicators suitable for monitoring treatment and outcome of BC in Denmark, a report reviewing the existing literature on the treatment of BC was made.¹ In 2015, DaBlaCa-data consisted of three process indicators and ten outcome indicators concerning the diagnostic and treatment quality of patients diagnosed with BC in Denmark. Indicators may change over the years as the database evolves. Patients with noninvasive tumors (urothelial papillomas or carcinoma

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in situ) are not included in the database. To avoid extensive manual registration of data, the database is largely based on secondary data from the Danish National Registry of Patients (DNRP) and the Danish National Pathology Register (DNPR).^{2,3} Consequently, extensive validation of the data has been done to secure that the algorithms used to identify patients diagnosed with BC (stage T1–T4) and the treatment provided for these patients had sufficient quality. Only variables regarding the cause of death, used for estimating cancer-specific mortality, and use of neoadjuvant chemotherapy are registered manually. Patients are identified in the database by their personal security number, making it possible to link DaBlaCa-data to other Danish registries if so desired with a purpose of research or monitoring the quality of treatment.

Study population

All patients diagnosed with BC in Denmark are included in the database. Inclusion is based on the data generated by the algorithms, which subtracts patients from the DNRP and the DNPR on a regular basis from all hospitals and private clinics in Denmark.

In 2013, 970 patients were referred or allocated to one of the five uro-oncological treatment centers treating BC in Denmark and were included in the database. Of the diagnosed patients, 26% were women. The median age was 74 years for women and 73 years for men.

Main variables

In 2013, a total of 970 patients were diagnosed with BC in Denmark. Among them, 512 (53%) were diagnosed with muscle-invasive BC (MIBC) and 458 were diagnosed with non-muscle-invasive BC (non-MIBC).

Survival

Of the 970 BC patients included in 2013, 698 were still alive 1 year after diagnosis, corresponding to a 1-year mortality

rate of 28% (95% confidence interval [CI]: 25–31). The national standard had been set to 35% prior to evaluation based on a literature review.⁴ All five treatment centers met the standard.

In 2013, cancer-specific mortality 1 year after BC diagnosis was 25% (95% CI: 22–27). Of the 970 patients, 226 had died because of BC within 1 year after diagnosis, whereas for 54 cases (6%), registration regarding the cause of death was missing. Therefore, cancer-specific death may in reality be higher than 25% but not higher than 31%. The national standard was set at 15% or less.⁵ Only one of the five treatment centers met the standard (Table 1).

A total of 300 patients, diagnosed in 2013, underwent cystectomy due to BC. At cutoff date (April 15, 2015), last date for data to be included in the preliminary report, 1-year follow-up after cystectomy was available for 270 patients, whereas data were missing for two patients. Therefore, 268 patients were included in this variable. Of them, 230 were still alive 1 year after BC diagnosis, corresponding to a 1-year mortality of 24% after cystectomy due to BC (95% CI: 21–28) (Table 2). The standard was set at 30% as the highest.⁶ All treatment centers met the standard.

In 2013, 1-year cancer-specific mortality after cystectomy due to invasive BC was 7% (95% CI: 5–11). A total of 19 patients were registered with BC as the cause of death, while 13 patients had missing data regarding the cause of death. The national standard was set at 12% or lower.⁷ All five centers met the standard.

Fraction undergoing neoadjuvant treatment

In all, 135 patients younger than 75 years were diagnosed with MIBC (stage T2–T4) and underwent cystectomy. Among them, 65 (48%) received neoadjuvant chemotherapy prior to cystectomy. The national standard was set at 25% or higher.⁶ All treatment centers met the standard.

Table 1 One-year cancer-specific mortality after invasive bladder cancer diagnosis on a national level and per treatment center

Center	Year						
	Per diagnose year		Missing information	2013		2012	
	Standard met	Dead/total		n (%)	%	95% CI	%
National	No	226/921	54 (6)	25	22–27	24	21–27
Herlev Hospital	No	59/236	10 (4)	25	20–31	28	23–35
Copenhagen University Hospital	No	37/170	12 (7)	22	16–29	18	13–25
Odense University Hospital	No	58/198	12 (6)	29	23–36	23	17–29
Aarhus University Hospital	No	55/207	17 (8)	27	21–33	27	21–34
Aalborg University Hospital	Yes	17/110	3 (3)	15	9–24	21	14–30

Note: The national standard was set at 15% or less.

Abbreviation: CI, confidence interval.

Table 2 One-year survival after cystectomy on a national level and per treatment center

Center	Per diagnose year		Missing information n (%)	Year			
	Standard met	Alive/total		2013		2012	
				%	95% CI	%	95% CI
National	Yes	230/268	2 (1)	86	81–90	87	82–90
Herlev Hospital	Yes	44/47	0 (0)	94	82–99	96	85–99
Copenhagen University Hospital	Yes	57/69	1 (1)	83	72–91	83	71–91
Odense University Hospital	Yes	38/45	0 (0)	84	71–94	86	76–93
Aarhus University Hospital	Yes	74/88	1 (1)	84	75–91	83	73–90
Aalborg University Hospital	Yes	17/19	0 (0)	89	67–99	95	76–100

Note: The national standard was at least 70%.

Abbreviation: CI, confidence interval.

Fraction undergoing cystectomy

In 2013, a total of 512 patients were diagnosed with MIBC (stage T2–T4) in Denmark. Among them, 166 (32%) were cystectomized within 6 months. We found a variation of 23%–40% in this proportion among the five centers. The national standard for this variable is still undetermined.

Post-cystectomy mortality

The 90-day mortality in patients undergoing cystectomy due to invasive BC in Denmark was found to be 3% (95% CI: 1–5) in 2013. The national standard was set at 7% or below and was met by all five centers.⁸

Postsurgical admission after cystectomy

For patients undergoing cystectomy due to BC in 2013, the median postsurgical admission including primary length of stay and readmissions after cystectomy during the first 90 days was 11 days (interquartile range [IQR]: 8–20 days). All admissions among the patients during the first 90 days were included, no matter the cause and the department. The national standard was set at a median admission of no more than 20 days.^{9,10} All five centers met this standard.

Oncological treatment

In 2013, 147 patients diagnosed with BC received their first radiation therapy with curative intent. Of these, 99 were still alive 1 year after the date of first radiotherapy. One patient had undetermined status and was not included. Thus, 1-year mortality after curative radiation therapy due to BC was 32% (95% CI: 24–39). The national standard was set at 40% or lower.¹¹ Two of the five centers did not meet the standard (1-year mortality of 42% and 43%, respectively). The other three centers met the standard (27%, 32%, and 31%, respectively).

Among the 147 patients receiving curative-intended radiation therapy in 2013, cancer-specific mortality was 23%. Thirty-three patients were registered with BC as the cause of death. Three patients lacked information regarding the cause of death. The national standard was set at 18% or less.¹² Only one of the five centers met the standard (11%) (Table 3).

Follow-up

By April 15, 2015, patients registered in DaBlaCa-data are followed for only 2 and 3 years (2012 and 2013). The follow-up is continuous for each patient and ends at death of that patient. The data presented in this paper are based on

Table 3 One-year cancer-specific mortality after first curative-intended radiation therapy due to MIBC on a national level and per treatment center

Center	Per diagnose year		Missing information n (%)	Year			
	Standard met	Dead/total		2013		2012	
				%	95% CI	%	95% CI
National	No	33/144	3 (2)	23	16–31	14	9–21
Herlev Hospital	No	9/44	0 (0)	20	10–35	3	0–14
Copenhagen University Hospital	Yes	2/19	0 (0)	11	1–33	12	3–31
Odense University Hospital	No	13/51	1 (2)	25	14–40	19	8–33
Aarhus University Hospital	No	8/24	1 (4)	33	16–55	26	9–51
Aalborg University Hospital	No	1/5	1 (17)	20	1–72	18	2–52

Note: The national standard was set at 18% or less.

Abbreviations: MIBC, muscle-invasive bladder cancer; CI, confidence interval.

a preliminary report including all patients diagnosed with BC in Denmark in the period between January 1, 2012 and December 31, 2013. DaBlaCa-data is an ongoing database enrolling all patients diagnosed with BC in Denmark from 2012 onward.

Examples of research

A validation report based on the validation of algorithms prior to the final establishment of DaBlaCa-data is in preparation. Further studies based on the results found in DaBlaCa-data are planned with a longer follow-up period.

Conclusion

DaBlaCa-data is able to identify Danish BC patients and monitor treatment and mortality. The preliminary DaBlaCa-data report showed comparable results between the five uro-oncological treatment centers responsible for the treatment of all patients diagnosed with BC in Denmark. Differences in mortality among the BC patients may reflect differences in the general mortality in different regions of Denmark.

The standard for cancer-specific mortality 1 year after BC diagnosis (15%) is believed to be underestimated. Most studies of the existing literature focus on cancer-specific mortality in patients who had received treatment due to BC. The DaBlaCa-data includes all patients with BC; hence, 15% is an underestimate in this database, though 15% is the best estimate when reviewing the literature. The high 1-year survival rate after cystectomy could reflect the fact that all the five uro-oncological centers have high and uniform standards for selecting patients for cystectomy and high quality of the surgical procedure. The board members of DaBlaCa-data expect to see more variation in cancer-specific mortality over time, due to longer follow-up periods. Until now, the treatment strategy has differed concerning the trend to choose radiation therapy. All five centers strive toward more uniform treatment protocols in the future than in the past. The median length of stay in a hospital post-cystectomy was very low compared to the standard. This again may reflect the high and uniform surgical standard among the five uro-oncological centers in Denmark.

The variation seen among the centers regarding cancer-specific mortality after curative-intended radiotherapy may reflect differences in patient selection to radiotherapy. The fact that two of the five centers were slightly under the standard concerning 1-year survival after curative-intended radiotherapy is believed to be insignificant.

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Disclosure

The authors report no conflicts of interest in this work.

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