Original Article

Evaluation of Data Completeness of the Prostate Cancer Registry after Robotic Radical Prostatectomy

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Abstract

Introduction: This study evaluated the data completeness in the registration of prostate cancer after robotic radical prostatectomy (RRP) in the Urological Cancer Registry at the Singapore General Hospital (SGH), and its compliance to the international standards of US Commission on Cancer (CoC). Materials and Methods: A certified cancer registrar reviewed all RRP cases between June 2003 and July 2008 in the Urological Cancer Registry at SGH. Results: A total of 365 cases were reviewed. The results showed that 351 (96.2%) of RRP patients' demographic data were captured and 321 (87.9%) of RRP patients were staged. According to the international standards of CoC for an academic institution, the requirement is to capture 100% of all cancer cases and stage at least 90% of them. As for data completeness, 317 (86.7%) of RRP details were captured as compared to the CoC standard requirement of 90%. Conclusions: The existing manual cancer registry does not fully meet the CoC standards. Hence, the registry increased sources of case-finding and used active case-finding. With improvements made to the data collection methodology, the number of prostate cancer cases identified has been increased by 52.1% from 215 in 2007 to 327 in 2009. The registry is expected to be fully compliant with the CoC standard with the recruitment of more full time cancer registrars when a new web-based cancer registry is in full operation.

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Key words: Case-finding, Computerised cancer registry, Data quality control, Manual cancer registry

Introduction

Cancer data can be abstracted manually by cancer registrars or extracted automatically from the electronic medical systems. There may appear to be nothing in common between a manual Cancer Registry dealing with a few hundreds of new cases a year, and a large, highly computerised Cancer Registry as both of the operating methods differ greatly. However, their functional components are identical and both of them carry out the same tasks: data collection, record linkage, data organisation, medium conversion, enquiry generation and follow-up, and data analysis.[1]

The Department of Urology at the Singapore General Hospital (SGH) established a Urological Cancer Registry (UCR) in 1980's. The registry is a special cancer registry[2] that collects and maintains data on all Urological cancers diagnosed and/or treated at Singapore General Hospital. The registry which has been practising manual case-finding,

data abstracting, data validating and data analysing for the past 20 years has been a critical and valuable source for clinical audit, research publications and clinical trials in the department. With the recent integration of more advance technology in the areas of medical record methods and computer sciences, it is essential and timely to modify and update the existing databases. Recently, the department undertook the opportunity to evaluate data completeness in the registration of prostate cancer after robotic radical prostatectomy (RRP) in the manual Urological Cancer Registry and its compliance with the international standards of US Commission on Cancer (CoC), which sets the gold standard for hospital-based cancer registries worldwide.

Materials and Methods

The CoC standard 3.2 requires Hospital-based Cancer Registries to follow CoC data standards and coding instructions - the current edition of Facility Oncology

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Registry Data Standards (FORDS).[3] The registry has designed a prostate cancer dataset according to FORDS revised for 2007, which includes the above 6 components of an abstract. Highly relevant to the specialty of Urology, the dataset is tailored to the needs for prostate cancer. Data elements such as International Prostate Symptom Score (IPSS), Quality of Life (QOL) due to Urinary Symptoms, Global assessment of Urinary Bothersome-ness Score, a 5-item International Index of Erectile Function (IIEF-5), and surgical details are incorporated into the Prostate dataset. All data in the registry database are coded.

Based on CoC standard 2.10, a registry must have a quality control plan to evaluate the quality of Cancer Registry data.[4] As a result, the UCR conducted a quality assessment to the registry. Between June 2003 and July 2008, the UCR had registered 1300 prostate cancer patients. Recognising that the CoC quality control plan requires a minimum of 10% of annual analytic caseload,[3] the UCR defined the scope of the evaluation as all 365 prostate cancer patients who underwent robotic radical prostatectomy (RRP) between June 2003 and July 2008 from the Hospital Operating Theatre Management (OTM). (Analytic cases refer to cases diagnosed and/or any course of treatment administered at SGH after 1980's). A certified tumour registrar (CTR), by the US National Cancer Registrars Association's Council on Certification, compared the 365 records in the OTM to the 1300 records in the UCR. The areas being reviewed included patient identification, cancer identification, stage of disease at diagnosis, first course of treatment and outcomes. Table 1 lists the detailed data items that were reviewed. The review focused on data completeness and compliance to CoC standards for each individual case.

The UCR has been focusing on updating the registration of prostate cancer after RRP. Data of patients who underwent RRP were most completed as compared with data of patients who underwent radiotherapy and/or hormonal therapy. If the completeness in the registration of prostate cancer after RRP could not meet the CoC standards, the registration of prostate cancer would not be compliant to the CoC standards.

Results

As shown in Table 2, the results indicate that the existing manual cancer registry does not fully meet the CoC standards.

Clinical outcome data for the RRP cases between June 2003 and July 2008 are as follows. Surgical margin positive rate was 47.1% (Table 3). It is not acceptable that 9.6% patients of surgical margin were not recoded. The UCR re-abstracted data on surgical margins from Histopathology reports. Surgical margin positive rate is 53.2% after the completion of the data abstraction of surgical margins.

Table 1. Data Items Reviewed in the Study

Category	Details
Patient Identification Data	Name
	NRIC (National Registration Identity Card)
	Date of Birth
	Preop IPSS
	Preop QOL
	Preop Global Assessment of Urinary Bothersome-ness
	Preop IIEF-5
Cancer Identification Data	Date of Diagnosis
	TRUS Biopsy / TURP Gleason Score
	Preop PSA
Stage of Disease at Diagnosis	Clinical Stage
	Pathological Stage
First Course of Treatment	Date of RRP
	Weight of Gland
	Nerve Sparing Status
	Total Operative Time
	Estimated Blood Loss
	Blood Transfusion
	Surgical Margin
Outcomes	30 day Mortality after RRP
	Complications of RRP
	Date of Last Contact
	Survival Status
	Postop PSA

Table 2. Summary of RRP Cases between June 2003 and July 2008 at Department of Urology, SGH

Category	Number of Cases	Percentage	CoC Standard Requirements for an academic institution
Eligible Cases Captured*	351	96.2%	100.0%[5]
Cancer Cases Staged	321	87.9%	90.0%[4]
Data Completed	317	86.7%	90.0%[6]

*Eligible Prostate Cases are required by CoC are malignancies with an ICD-O-3 behaviour code of 2 or 3, which exclude prostate PIN III)[7]

Table 3. Surgical Margin Positive Rate for RRP Cases between June 2003 and July 2008 at Department of Urology, SGH

	No of Cases	Percentage
Surgical Margin (+)	172	47.1%
Surgical Margin (-)	158	43.3%
Surgical Margin not recorded	35	9.6%
Total	365	100.0%

Table 4. Urinary Continence after RRP between June 2003 and July 2008 at Department of Urology, SGH

	At 3 Months		At 12 Months	
	No of Cases	Percentage	No of Cases	Percentage
Continent	172	53.4%	235	84.2%
Incontinent	144	44.7%	33	11.8%
Continence Unknown*	6	1.9%	11	4.0%
Total Cases Under Data Follow-up†	322	100.0%	279	100.0%

*Due to patients lost to follow-up at the Department of Urology, SGH

†To indicate number of cases that data were collected by the UCR

There is a significant difference between the true positive rate (53.2%) and the original positive rate (47.1%) (P = 0.000). Urinary continence rate at 3 months versus at 12 months is 53.4% versus 84.2% (Table 4). Potency rate at 3 months versus at 12 months is 4.1% versus 12.1% (Table 5). Median data follow-up period is 1.6 years (± 1.5 years). One hundred and thirty-four (36.7%) patients' data on cancer status were followed up for more than 2 years. PSA recurrence rate, never disease free rate and systemic recurrence rate at 2 years after RRP were 8.2%, 2.2% and 0.7% respectively. Six (1.6%) patients' data on cancer status were followed up for more than 5 years. PSA recurrence rate, never disease free rate and systemic recurrence rate at 5 years after RRP were 16.7%, 16.7% and 0% respectively. There were no deaths for all Singapore Residents of the RRP patients between 2003 and 2008 based on a recent report from Singapore National Disease Registry on 30 June 2009.

Discussion

As shown in the quality data audit, the manual cancer registry did not meet the CoC standard requirements in all 3 categories. Four major factors below caused the incompleteness of the registration.

First, case-finding was not completed. Cancer cases were identified only by positive pathology reports sent from the Department of Pathology at SGH and case notes sent by Urologists from the Department of Urology (Fig. 1a). Other sources of case-finding such as operative reports, disease index and radiation oncology log were not used. Therefore, a system to monitor prospective cases has been in place in the Department of Urology to increase the capture rate of eligible cases from 2008.[8] The registry has included 8 case-finding sources: (i) Disease index from outpatient administrative system (OAS), (ii) Disease index from inpatient discharge log, (iii) Operating Theatre Management System (OTM), (iv) Pathology reports, (v) Radiation oncology log, (vi) Tumour board, (vii) Uro-pathological conference, (viii) X-ray conference (Fig. 1a).

Second, no active case-finding was involved (Fig. 1b). All prostate cancer cases were sent to the UCR from the Department of Pathology and by Urologists on a voluntary basis. In a study by Gajalakshmi et al,[9] the completeness of cancer registration was 96% by active methods. The UCR has started active case finding methods to increase the completeness from year 2008[8] (Fig. 1b). The registry personnel retrieved all source documents and then screened to identify eligible cases.

By increasing sources of case-finding and using active case-finding, the number of prostate cancer cases identified has been increased 52.1% from 215 in 2007 to 327 in 2009.

Table 5. Potency after RRP between June 2003 and July 2008 at Department of Urology, SGH

	Baseline		At 3 Months		At 12 Months	
	No of Cases	%	No of Cases	%	No of Cases	%
Potent (IIEF-5 >=17)	197	54.7%	13	4.1%	33	12.1%
Impotent (IIEF-5 <17)	158	43.9%	295	92.5%	219	80.2%
Potency Unknown*	5	1.4%	11	3.4%	21	7.7%
Total Cases under Data Follow-up†	360	100.0%	319	100.0%	273	100.0%

*Due to patients lost to follow-up at the Department of Urology, SGH

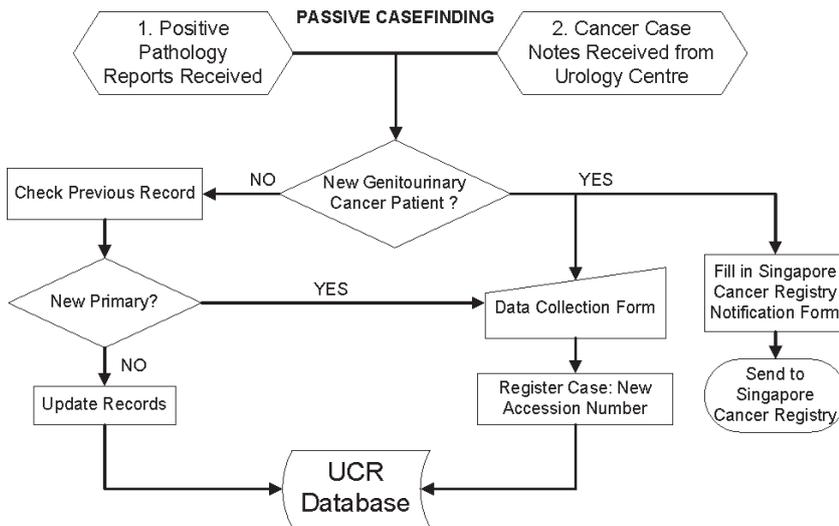†To indicate the number of cases that data were collected

PASSIVE CASEFINDING

1. Positive Pathology Reports Received

2. Cancer Case Notes Received from Urology Centre

New Genitourinary Cancer Patient ?

NO — Check Previous Record

YES

New Primary?

YES — Data Collection Form

NO

Update Records

Register Case: New Accession Number

Fill in Singapore Cancer Registry Notification Form

Send to Singapore Cancer Registry

UCR Database

Fig.1a. The old workflow of the UCR operating procedure.

1. Pathology Reports

2. OAS

3. Inpatient Discharge Log

4. OTM

5. Radiation Oncology Log

6. Tumor Board

7. Uropathological Conference

8. X-Ray Conference

Genitourinary Cancers?

NO — Outside of current scope

YES

New Genitourinary Cancer Patient ?

NO — Check Previous Record

YES

New Primary?

YES — Data Collection Form

NO

Update Records

Register Case: New Sequence Number

Data Collection Form

Register Case: New Accession Number

Fill in Singapore Cancer Registry Notification Form

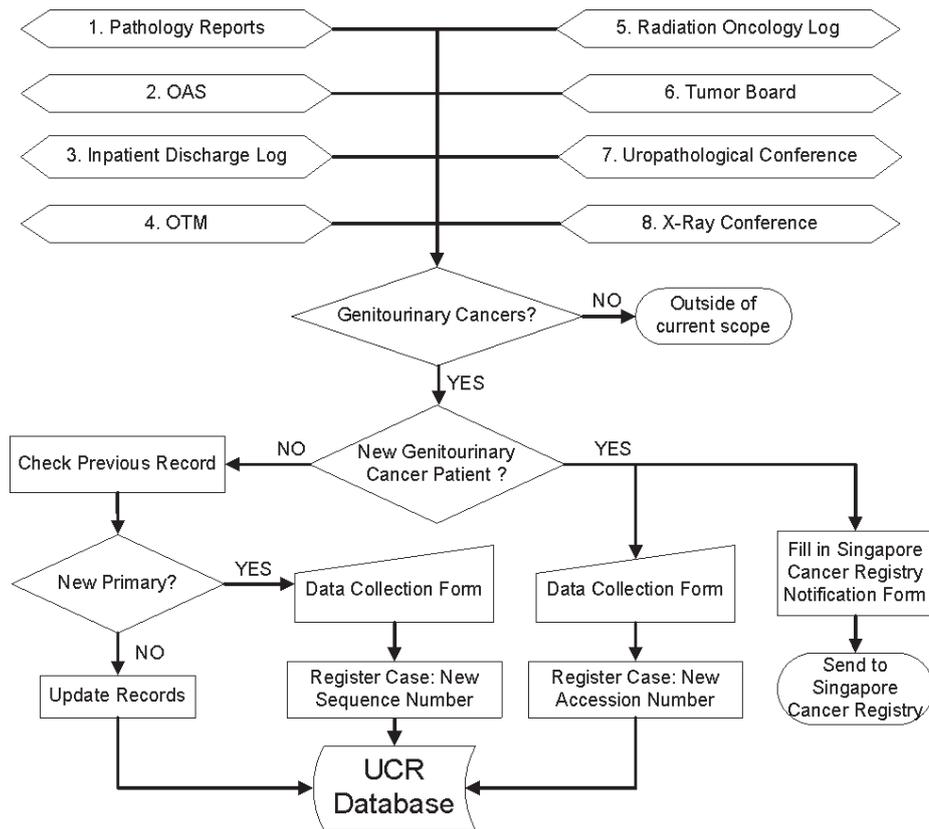Send to Singapore Cancer Registry

UCR Database

Fig. 1b. The new workflow of the UCR operating procedure.

Third, there were no full time cancer registrars working for the registry during that period of time. Cancer cases were registered using pen and paper by administrative staff. The registration of eligible cancer was often inconsistent, thus, incomplete registration of eligible cases was inevitable. Furthermore, data were abstracted by medical officers at the Department of Urology upon initial diagnosis so limited data were recorded in the registry. Treatment details and outcomes were missing from the registry. Therefore, the Department has recruited one certified cancer registrar to enhance the functions of the UCR from 2008. Two more full time staff were expected to join in the UCR in June 2010. The registry is expected to have 100% eligible prostate cancer cases captured for new cases, more than 90% of them staged and 90% of data completeness of prostate cancers diagnosed from 2005 to 2009 by March 2011.

Fourth, the UCR was purely a manual cancer registry with limited manpower. Though there is no standard man-hour needed in data collection, insufficient man-hour will cause errors in data collection. On the other hand, too many man-hours will reduce registry productivities. In our practice, 2 man-hours are adequate to abstract/update one prostate cancer case. The UCR has 4300 prostate cancer cases with 327 new cases increasing yearly. It is impossible to keep all cases in the registry updated at least once per year by 3 cancer registrars. But computerisation provides the possibilities of increasing satisfactory from data completeness. A computerised Cancer Registry is able to automatically generate data from record linkages such as hospital electronic medical records system so that it can reduce healthcare costs and increase efficiency.[10] In a study by Paolo Contiero et al,[11] 98.7% of all eligible cases found were picked up by the automated system. In another study by Kyllonen et al,[12] the Finnish Cancer Registry, which is a computerised registry, achieves more than 99.9% coverage of all eligible cases. Computerisation makes it possible to capture all urological cancer cases in the registry.

However, comprehensive urological clinical data such as IPSS, IIEF-5, and clinical staging are not captured in the hospital electronic medical record system. It is not practical to fully computerise the Urological Cancer Registry at SGH as such clinical data must be complemented by manual means of data capture at present.

A combination of manual and computerised cancer registry is currently the optimum solution for our new web-based cancer registry. The department is in the process of setting up the new web-based cancer registry database. The database will be hosted on one of the servers on campus for multi-users from various institutions within the campus, with security features adequate to protect the confidentiality of data and security of the system. The Singapore General Hospital is part of the Singhealth campus of health institutions, including the National Cancer Centre in which Medical and Radiation Oncology are based. The web allows for collaboration among Departments of Urology, Pathology, Radiation Oncology and Medical Oncology to increase completeness of case-finding as well as diagnostic, treatment and outcome data. We aim to link the database to the SGH electronic medical records system by 2015. Data items that are not captured in electronic medical records system will be manually abstracted from patients' case notes. Data items that are captured in electronic medical records system will be imported directly from the electronic medical records system into the registry database automatically.

From the quality control perspective, this study has some limitations because it assesses data completeness only. The UCR will assess data accuracy and abstracting timeliness separately. The registry is expected to be fully compliant with the CoC standards with enhanced registry infrastructure such as completing case-finding sources, hiring certified and dedicated registry staff, and upgrading the current manual cancer registry into a combination of manual and computerised cancer registry. When the new web-based cancer registry is fully in operation, the UCR is expected to better serve Urologists and researchers for clinical audit, research publications and clinical trials in the Department of Urology.

Conclusions

The existing manual cancer registry does not fully meet the CoC standards. Thus, the registry increased sources of case-finding and used active case-finding. With improvements made to the data collection methodology, the number of prostate cancer cases identified has been increased by 52.1% from 215 in 2007 to 327 in 2009. The registry is expected to be fully compliant with the CoC standard with the recruitment of more full time cancer registrars when a new web-based cancer registry is in full operation.

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